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**The spoilt blood that needs nourishment: Managing TB in the context of HIV/AIDS,
food insecurity and social inequalities in Mbekweni, Paarl**

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PLAGIARISM DECLARATION

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ABSTRACT

The use of ethnographic methods unravelled that families face multiple problems in managing the converging impact of TB, HIV/AIDS and food insecurity. The emerging themes in the conversations of many people; ‘the food that nourishes the blood’ and ‘if there was no grant we would die of hunger’ indicates that financial security and adequate nutrition are pivotally important for strengthening the immune response of people affected with TB and HIV illness. The fieldwork took place between October 2006 and September 2007 in Mbekweni Township, outside the Paarl district in the Western Cape. Rapid participatory methods included six focus group discussions with key informants to understand the contextual background of timelines of food economy, seasonal calendars of employment and cash activities, wealth and well-being of the community. Case materials of ten people (five with TB, and five with TB and HIV) and their families, and ten comparative families without TB to explore whether the presence of TB pushed families deeper into poverty, were compiled through semi-structured interviews and observation techniques.

The physical debility from TB illness prevented the sick from earning a wage, self-care and mobility. Some households were anxious about death and funeral costs as they lacked substantial safety networks and dependent largely on social grants. Payments for transport costs to health care centres, repeated visits to private doctors before TB diagnosis, healing rituals and ‘special’ foods left families economically drained. TB and HIV experienced increased hunger associated with TB and ARV medication and put additional demands on their families for ‘special’ foods high in protein and carbohydrates that were not always available in the home. Families who did not experience TB were not noticeably better off as they experienced other diseases for example, high blood pressure, diabetes, asthma, arthritis and stroke, but these diseases did not put pressure on them for ‘special foods’, and were not associated with HIV (except in one family where there was a small boy with HIV).

This study found that people were struggling with social problems other than ill health namely, death (not related to TB and HIV), unemployment, food insecurity, poor housing, drugs, alcohol abuse, crime, violence, and gender inequality. The study recommends prompt diagnosis of TB and VCT to ease the cost burden on families, as they lack health care insurance. NGOs that provide food aid are encouraged to consider the long process of accessing disability grants and provide food aid to protect against hunger while people are waiting for their grants. Clinics need to strengthen their collaboration with food aid organisations to ensure people do not abandon their treatment due to hunger. Interventions at the community level need to consider development projects that will enable people to sustain livelihoods, and protect themselves from factors that make them vulnerable to ill health.

ABBREVIATIONS

ADP	Area Development Programme
AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretrovirals
CWD	Catholic Welfare Development
DOTS	Directly Observed Therapy Short course
DTTC	Desmond Tutu TB Centre
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
MDR	Multi-Drug Resistance
MSF	Medicins Sans Frontiers
NGO	Non-Governmental Organisation
PLWH	People Living with HIV/AIDS
RDP	Reconstruction and Development Program
TB	Tuberculosis
VCT	Voluntary Counselling and Testing
XDR	Extreme Drug Resistance

TABLE OF CONTENTS

PLAGIARISM DECLARATION	I
ACKNOWLEDGEMENTS.....	II
ABSTRACT	IV
ABBREVIATIONS	VI
 CHAPTER ONE: PREVALENCE OF TB AND HIV/AIDS: CONTESTED TERRAINS	 1
1.1 THE BURDEN OF ILLNESS	1
1.2 THEORETICAL CONSIDERATION	7
1.3 AIMS OF THE STUDY	9
1.4 BACKGROUND TO THE STUDY	10
1.5 METHOD OF FIELDWORK	12
1.5.1 Selection of participants	12
1.5.2 Getting to know the community.....	14
1.6 CHAPTER OUTLINE	15
 CHAPTER TWO: IGAZI ALILIHLAGA.....	 19
2.1 INTRODUCTION.....	19
2.2 CASE STUDIES.....	22
2.3 PHYSICAL EXPERIENCES OF TB AND HIV ILLNESS	36
2.4 WHAT CAUSES MY ILLNESS?.....	38
2.4.1 Mistrust.....	40
2.4.2 Blaming Others.....	40
2.5 SEARCHING FOR DIAGNOSIS AND CURE.....	41
2.6 THERAPEUTIC OPTIONS.....	43
2.6.1 The food that nourishes the blood.....	45
2.6.2 Not my normal body size: Implications for TB, HIV disclosure and Stigma.	51
2.6.3 TB and HIV Disclosure.....	52

CHAPTER THREE: SUPPORT NETWORKS	56
3.1 INTRODUCTION	56
3.2 IMINI YONCUMO	57
3.2.1 <i>Negotiating Illness</i>	58
3.2.2 <i>External support</i>	61
3.2.3 <i>Caring as reciprocity</i>	63
3.2.4 <i>Maintenance of health: agency and control</i>	72
 CHAPTER FOUR: THE WIDER CONTEXT OF VULNERABILITY	 76
4.1 INTRODUCTION	76
4.2 CASE STUDIES OF THE TEN FAMILIES WITHOUT TB	76
4.3 MBEKWENI: A RESEARCH SITE	81
4.4 LIMITED SOCIAL NETWORKS	84
4.5 TRUST AND COHESION THREATENED BY WITCHCRAFT ACCUSATIONS	89
4.6 VIOLENCE AND CRIME	92
4.7 COPING OR STRUGGLING?	94
 CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS	 99
 REFERENCES	 101

LIST OF TABLES

TABLE 1: PROFILES OF PEOPLE WITH TB AND HIV	22
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TABLE 2: SOCIO-ECONOMIC STATUS OF FAMILIES AFFECTED WITH TB AND HIV	68
---	----

LIST OF FIGURES

FIGURE 1: FAMILY MEALS	48
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FIGURE 2: ENVIRONMENTAL ISSUES.....	83
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CHAPTER ONE

PREVALENCE OF TB AND HIV/AIDS: CONTESTED TERRAINS

1.1 The burden of illness

Xoza¹, a 30-year-old man, was looking forward to spending the Christmas holidays of 2006 in his village in the Eastern Cape and coming back for his part time employment in Cape Town. He coughed a little in Cape Town and had no idea that this could be the onset of TB symptoms. His cough became serious at home with other symptoms arising such as sweating, chest pains, and loss of appetite, weight and energy. Because he had bought furniture for his mother, he thought people had become jealous and gave him 'idliso'-poison through witchcraft. He was also worried that his family would suspect he has 'this common disease - AIDS'. His mother encouraged him to go to the local clinic. He received medication and a sputum jar but he could not produce sputum. He went back the following day and found the clinic closed. In January, his mother sent him back to be with his father, Malangeni, in Mbekweni. Malangeni said that when he first saw Xoza's condition he thought he would die. Malangeni thought Xoza had TB because of his smoking. He encouraged Xoza to go to the clinic. However, Xoza's brother took him to a private doctor in Paarl, which cost R140. The doctor gave him medication and referred him to Mbekweni clinic. A week later, he found out at Mbekweni clinic that he had TB and he started treatment immediately. Malangeni bought Tim Jan, a herbal aloe mixture for Xoza to drink but Xoza refused to use it since he found it bitter and it loosened his stomach.

¹ I use pseudonyms throughout the thesis to honour trust as the informed consent stipulated that the rights, interests of participants, sensitivities and privacy of the information would remain confidential during fieldwork and when writing up the findings not to cause any harm to participants' social and psychological well-being (Anthropology Southern Africa, 2005).

He said it was not right to drink the mixture simultaneously with TB medication and considered that as 'killing' himself. When he was ill, he did not move around, he began to put on weight in his second month of treatment and began to visit friends. He experienced increased hunger and emphasised that, *'taking tablets without eating can make you drunk, knock you down and could even kill you. It is hard these days because there are no jobs, I am thankful that I go to bed with a full stomach because ayilolizwe eli- it is not the perfect world, life is hard out there.'*

TB is a lung infection caused by a germ *Mycobacterium* that spreads from one infected person to another through talking, coughing and sneezing – an airborne germ that can infect anyone. TB is a disease with a long history rendering it a subject of rival explanations in socio-medical practice. It has had a particular devastating impact on poor populations (Farmer, 1999, Fassin, 2003, Marks, 2002, Stillwagon, 2003). Samson (1999) reports that a medical scientist commented in the *New Scientist* journal in the 1940s, that

'Certainly we know that Mycobacterium TB causes it, but the rest is a mess'

Another bacteriologist Louis Pasteur expressed similar views about the complexity of TB: *'The microbe is nothing, the terrain is everything'* (cited by Mosley, 2004)

As if the TB plague had not challenged society enough, the emergence of HIV/AIDS transformed the pathogenesis of TB. While HIV has a different mode of transmission to TB, biomedical examination found the two diseases to work in synergy to degenerate bodily cells. The high prevalence of TB has been associated with the rapid spread of HIV/AIDS, new strains of TB, namely MDR and XDR-TB, which are resistant to first and second line drugs and threatens the lives people infected with TB and HIV. South Africa has experienced high levels of TB and HIV/AIDS despite free access to TB and more recently, HIV services and chemotherapy. The national TB cure rate now stands at 57%, lower than the World Health Organisation's recommended rate of 85%. Over 50% of people with TB in South Africa are also living with HIV (Achmat, 2005, MSF, 2006; Stop TB, 2007). These diseases are more prevalent in the African population.

The statistics presented above often submerge the human experiences of TB and HIV as revealed in Xozza's narrative above. It is important to remember that an interaction of factors within the family, social environment and health care systems contribute to the successful control of TB.

The socio-medical and anthropological literature I have cited, suggests that the unremitting levels of TB and HIV/AIDS among Africans can be traced through their cultural beliefs, regarding proximate causes of ill- health and ultimate causes. The literature reports that these beliefs force many Africans to seek relief through traditional healing practices before western biomedical practices. Similarly, the literature states that cultural beliefs about sexuality and gender relations often undermine the practice of safe sex within monogamous sexual relationships. The researchers recommend health education as a mechanism to correct misconceptions about the causes, transmission and treatment of TB, and promotion of safe sex (De Villiers - Herselman, 1991, 2002, 2007, Edginton et al, 2002, Meijer-Weitz et al, 2001, Peltzer & Promtussananon, 2005). To counter these conclusions, a study done by a group of physicians (published in the Journal of American Medical Association, 1991) found that the main cause of the prevalence of many diseases among Blacks in South Africa were poverty, widespread hunger and malnutrition.

Similarly anthropologists Paul Farmer, (1999); Ho, (2004) and Shretha Kuwahara et al, (2004) reviewed a set of social science literature on TB transmission and adherence in other less developed countries, namely India, Latin America, South East Asia and other African states. They found that these studies attributed high levels of TB and non-adherence to treatment, to cultural beliefs that influenced whether people sought diagnosis or use alternative therapy instead of Western biomedical cure. Concerned with a universalised cultural interpretation of ill health of marginalised populations, Farmer and others followed up on these findings and conducted an ethnographic study in Haiti and Honduras where public health services were failing and people lived in poverty.

They found that beliefs about the causes of TB had not interfered with taking TB medication and largely socio-economic barriers influenced treatment-seeking behaviour. Additionally, Adriaanse and Barhoons (1992) found non-compliance in central India to be associated with socio-economic factors. In a similar study of TB among immigrant Chinese labourers in New York City, which attributed the prevalence of TB to cultural beliefs, Ho (2004) found that global, environmental, cultural and politico-economic forces were responsible for TB among immigrant Chinese. Farmer (1999, 2000) has criticised social scientist for failing to provide an influential behaviour change model to replace the widely used cognitive model of health beliefs that draws heavily on psychology. He further argues that anthropologists continue making 'immodest claims of causality' by purporting to be 'experts in local knowledge', in an uncritical way which pays less attention to social theory while the trajectory of the epidemics show a link between biological and social forces.

Historical studies in other parts of the world and in South Africa began to unravel the terrains through which individuals have embodied TB and HIV/AIDS pathologies (Packard, 1989, Fassin, 2003, Farmer, 1999). These studies bear evidence that explaining TB and HIV spread solely in conventional medical terms and individual behaviour and not in the social context of affliction is a methodologically fallacy. Historian Thomas McKeon², physician, pathologist and social anthropologist Rudolph Virchow, and historian turned microbiologist Rene Dubois argued that poor socio-economic conditions compounded the physiopathology of the mycobacterium. Empirical studies in Europe and North America supported these views about the link between TB and social conditions. After the discovery of the drug Streptomycin, the re-emergence of TB affected mainly the poorer sections of the inner cities such as homeless shelters, prisons, public hospitals and other marginalised populations. Virchow found that the outbreak of

² The decline of mortality due to TB disease in Europe and North America in the 1940s, was attributed more to peoples immune resistance as a result of improved nutrition, housing and working conditions, than the effectiveness of Streptomycin drug as a cure for TB (Gandy & Zumla, 2003; van Helden, 2003, 2004; Nguyen & Peschard, 2003, Gandy & Zumla, 2003; van Helden, 2003, 2004; Nguyen & Peschard, 2003).

a typhus epidemic in Upper Silesia in 1848 was a result of poor living conditions (cited by Tan & Brown, 2006).

The findings reported above support Farmer's assertions that large-scale forces, namely colonialism, industrialisation, capitalism, and apartheid in the case of South Africa are forms of structural violence that produced social inequalities. Entrenched in these social transformations were political economic relations of domination and subordination along the lines of race and class. Political economy is a system that regulates private ownership of capital, flow and exchange of commodities. The major sources of capital accumulation in South Africa have been the agricultural, mining and industrial sectors. The negative effects of this system in South Africa was the exclusion of Black people from owning capital which made them a major source of wage labour, under extremely oppressive conditions which compromised the health of indigenous people and the labour force (Magubane, 1982, Ramphela & Wilson, 1989, Packard, 1988).

The historical practice of social medicine in South Africa has been criticised for orchestrating the race paradigm from the era of colonial expansion through to the apartheid era. Butchart (1997) draws on Foucault's analysis of the Birth of the Clinic (1973) to chart the creation of the 'African or Bantu patient' in clinical medicine, as it was perceived to be different from the European body and therefore required different health care practice. Unterhalter (1982) asserts that health statistics has been a useful barometer of inequalities between different racial groups in South Africa, as the highest burden of disease morbidity and mortality has always been borne by Blacks. The historical context of the skewed burden of diseases in South Africa has been dealt with extensively by Packard, 1988; Ramphela and Wilson, 1990; Pronyk, 1999, Unterhalter, 1982, Yach, 1988, Anderson, 1990, Butchart, 1997, Marks, 2002, Marks and Anderson, 1988; 2002, Magubane, 1982, Myer et al, 2004, Fassin, 2003, 2006.

This literature highlights that the health of the majority of African adults and children has been undermined by structural factors namely, unemployment, low income, poor living conditions, inadequate health care services and low levels of literacy.

TB and syphilis (a sexually transmitted disease) in gold mines and male migrant labour hostels in the 1930s and 40s, engendered a discourse between mine authorities, doctors and scientists. The authorities questioned whether the underdeveloped immunity to withstand the bacilli brought by European settlers or poor living conditions in the mines caused high rates of TB among Blacks (Packard, 1988; Myer et al, 2004). The argument about high levels of syphilis was that the Blacks' genetic disposition or their lascivious behaviour caused the diseases. Improvements in living conditions, wages and compensation for ill health of White migrant labourers resulted in good health. Those of Black miners remained the same and TB persisted in this population. However, the mine authorities still searched for answers to the plight of Black miners. Subsequently the authorities introduced a system of 'tubercularization', which meant that migrants had to be exposed longer to the bacilli so that they developed an immunity to resist illness without any medical support. The migrants whose lives deteriorated because of TB were sent back home to recuperate as the authorities believed that the 'reserves' or homelands had less disease than the urban cities. Thus, migrants were taking TB and venereal diseases back to the then so-called 'healthy reserves' (Myer, et al, 2004; Packard, 1989). Epidemiologist Sydney Kark and anthropologist Bill Watson have countered the notion of genetic disposition and found that the migrant labour system and poor socio-economic conditions facilitated the spread of syphilis in rural communities of Natal in the 1940s and 50s. Kark recommended that the same improvements for the White communities could also benefit the health of Black communities (Myer et al, 2004).

Since Farmer has argued that the behavioural and cultural frameworks of TB and HIV/AIDS have overlooked the wider social context of vulnerability, some social scientists have called on a paradigm shift from an interpretive point of view to a more critical analysis of infectious diseases and their control.

For instance, Porter et al, (1999) began to propose an infectious disease policy that should look at the process of managing and controlling diseases rather than focusing on disease outcomes, a process that facilitates the production of long-term healthy communities.

Since the finding that TB and HIV work in synergy, several scholars have challenged the Directly Observed Treatment Short Course strategy as the only mechanism to reduce TB (Corbett et al, 2005, Worley, 2006, Pronyk, 1999, Fassin, 2003, Hunter, 2005; Marks, 2002). The Stop TB Partnership, a division of the WHO has recognised the limitations of the DOTS approach for some time and, in their plan for 2006-2015, has called on all National TB Programs to address poverty and equity to access health care.

Herselman (2002) affirms that since the late 1990s, medical anthropology has moved towards a critical perspective of health inequalities, and the link between TB and HIV has strengthened this shift and became a focal point in anthropological investigation. Although this claim may be true in other parts of the world, in South Africa, the medical anthropological literature that critically examines the link between TB, HIV/AIDS and poverty is scant. A few qualitative studies have been conducted on barriers to health seeking behaviour (Westaway & Wolmarans, 1994, Pronyk et al, 2001), adherence to TB treatment (Munro, et al, 2007) and on adherence to anti-HIV drugs in South Africa (Nachega et al, 2006). These studies found that social and material support, lack of money to treatment centres, food insecurity, stigma, and the choice between going to work or treatment centres prevented people from maximising their health. While these studies provide insight into the social circumstances of people with TB and HIV, their analysis is mainly descriptive of risk factors, and a question remains, why this literature does not look beyond this public health standpoint?

1.2 Theoretical consideration

I draw inspiration from the works of critical scholars such as Stillwagon, 2003, Bates et al, 2004, Mosley, 2004, Kalipeni, 2000, Porter et al, 1999, Marks, 2002, Pronyk, 1999, Fassin, 2003, Nguyen & Peschard, 2003, AIDS Analysis Africa, 2001, EQUI-TB, 2005, Farmer, 1999, Hunter, 2007, Scheper-Hughes & Lock, 1987. These scholars argue that an application of a vulnerability perspective that takes into account broader socio-economic factors explains better the unprecedented rate of TB and HIV/AIDS.

I argue that elevating “African cultural beliefs” as a variable that explains hindrances to

TB and HIV control strategies conceals a multitude of factors that facilitate susceptibility to these diseases. Without denying that the mycobacterium germ is necessary for TB infection and that unprotected sex causes HIV infection, I argue that progression from TB and HIV infection to TB and AIDS illness and the premature death of people living in poor settings require rigorous analysis. The vulnerability framework speaks to Farmer's concept of 'structural violence'. Ronald Frankenberg emphasises a paradigm shift from 'the making individual of disease' which means focusing on individual clinical symptoms to 'the making social of disease' -through the recognition of the interaction of social relations, behaviours, roles and the meanings attached to individual experiences of the disease (cited by Singer, 2004). Pronyk et al (1999) support a shift from "framing TB and HIV/AIDS in terms of 'risky behaviours' to vulnerability by tracing TB and HIV/AIDS illness and death among the poor to the socio-political and economic factors. The core of the vulnerability framework seeks to integrate and extend the social epidemiological framework in order to include the psychosocial, ecological and political economic determinants of health and diseases.

Biosocial practitioners argue, poor nutrition and other psychosocial stressors compromise the immune system, and render people more vulnerable to infectious and parasitic diseases (Stillwagon, 2005). Villamor et al (2006), Paton & Ng (2006) found that a person who is 10% underweight and infected with TB has a threefold higher risk of developing diseases. Weight loss is one of the important features of TB illness and a risk of premature death of people with TB and HIV. Therefore, people with TB and HIV need certain micronutrients to strengthen their immune response (Stillwagon, 2005, Lemke, 2005, Hunter et al, 2003, van Helden, 2003). However, in response to the health minister's insistence that nutrition could delay the need for Anti-retroviral medicine, 15 members of the Academy of Science of South Africa reviewed for nearly 2 years more than 2000 studies on the role of nutrition in the HIV and TB pandemics. The members reported that the studies showed no evidence that nutrition alone was the cure for HIV and TB, and neither could prevent these diseases.

However, the studies reviewed indicated that there were positive outcomes for people who took medication with better nutrition (www.assaf.org.za, 2007). As Professor Jimmy Volmink, a clinical researcher at the University of Stellenbosch who proposed the study and participated in the panel, explains, “The intake of micronutrients, such as carbohydrates, fats and proteins, was a strong indicator as to how fast people living with HIV and on treatment would progress to AIDS”. Nevertheless Volmink said studies on the role of nutrition in TB and HIV were rare. A few available studies conducted in high-income reveal that people have better access to good nutrition and health care. He queried the feasibility of such studies in lower income settings, moreover in a complex socio-economic setting like South Africa. Despite being food secure on a regional level, South African poverty rates shows that in 2005, 43% of African’s homes were food insecure and 18 million children lived in extremely unfavourable conditions (Khoza, 2007). These findings suggest that most African families suffer from malnutrition and are at risk of diseases associated with poverty, despite the government’s efforts to reduce poverty in the form of social grants.

1.3 Aims of the study

As mentioned above, epidemiology has long recognized the importance of good nutrition for protection against diseases. This study explored food issues pertinent to TB and HIV illness, and how families cope with nutritional requirements of people infected with TB and HIV. The findings cited above that nutrition can mitigate the effects of TB and HIV/AIDS provide the basis for testing the study hypothesis: poor families have a limited capacity to cope with the trajectory of TB illness in the context of food insecurity and HIV/AIDS without external welfare support.

I asked what type of food is available before having TB, with TB and, without TB. I asked if there were any special diets for people with TB, and what demands people put on families for special and additional food supplies I also explored sources of income and kinds of coping strategies people drew on before having TB, and after TB was contracted.

People and communities exist within broader social, health and economic systems. In turn, the maintenance of health becomes a lens for examining the interactions between people and their social environment (Berman et al, 1994).

Epidemiologists argue that the concentration of social ties in poor settings implies trust and social cohesion, and therefore collective action to deal with diseases produces healthy communities (Goudge & Govender, 2000, Harris, 2007, Francis, 2006, Booth et al, 1999, Nguyen & Peschard, 2003). However, I argue that the assumption that community trust and cohesion leads to healthy communities masks the experiences of people infected with TB and HIV. For example, considering the secrecy around one's illness, especially HIV/AIDS, it may be difficult for people to seek external support. Additionally in an environment with limited material resources, it was also critical to understand household events and changes over time, decisions and actions taken to use internal and external resources to cope with TB and HIV/AIDS illness. As Francis (2006) asserts, the challenge for sociologists and anthropologists is to understand the shocks experienced by the poor as not only probabilities of socio-economic trends but as a constellation of factors that leave a pattern of vulnerability which may be understood better when grounded in the political economy at the local, national and international levels.

1.4 Background to the study

In 2005, I worked with three others; carrying out a social science enquiry within a community-randomised trial - the ZAMSTAR project (Zambia South Africa TB and AIDS Reduction Trial) -conducted by the Desmond Tutu TB Centre of Stellenbosch University over a period of six years (2004-2010), in eight Western Cape sites, including Mbekweni. The ZAMBART Project and the London School of Hygiene and Tropical Medicine are also conducting the same trial in Zambia. Bill and Melinda Gates Foundation funded the ZAMSTAR study that aims to measure the effectiveness of three different approaches to reduce TB in poor communities with high HIV prevalence.

Between October 2005 and February 2006, the social science team conducted a Broad Brush Survey to gain a rapid understanding of many aspects of Mbekweni life. The team conducted intensive fieldwork for two weeks to provide the BBS with an in-depth qualitative understanding of local experiences of TB. Preliminary findings from intensive fieldwork for ZAMSTAR indicate that central to the discourses of TB illness were problems about food as expressed in the following quotes. 'I cannot stop thinking about food and eating' (female with TB- 28 years), 'there is often no bread or anything to eat, we really struggle' (Male with TB- 48 years), 'how am I going to survive if my TB grant is withdrawn by the state' (Female with TB- 44 years) (Unpublished data: DTTC, 2005-2006). It is against this background that I became interested in an in-depth understanding of the link between TB and food, and since TB is a chronic illness, to understand how people manage over time. As Stanley Yoder (1997) insists, if anthropologists seek to understand the relation between local knowledge and practice of health, it is crucial to realise that extensive fieldwork can produce relevant knowledge around local conceptions of health and practices.

My research has been conducted within a site for a medical trial but it was funded separately by RENEWAL (Regional Network on AIDS, Rural Livelihoods and Food Security) a project of IFPRI (International Food Policy Research Institute). Dr Virginia Bond of ZAMBART won the grant to carry out a comparative study of these themes in Zambia and in South Africa, and to give two African social scientists the opportunity to do an M. Phil. It was in this way that; I seized an opportunity to use the fieldwork data towards an M. Phil. In addition to the skills I obtained through various trainings at DTTC namely a GCP (Good Clinical Practice) ethics course and Focus Group Facilitation and Individual Interviewing, in the first year, I took an ethnographic research methods course, and I developed my own proposal within the framework of the RENEWAL grant. As a novice anthropologist, I have also benefited from working with Pauline Peters, a medical anthropologist and her team in the field in rural Malawi.

In Zambia, I learned to take anthropometric measurements from Debra Crooks, a nutrition anthropologist and associate professor of anthropology at University of

Kentucky, USA who has done ethnographic work in Zambia for many years, focusing on child growth and household coping strategies. My counterpart Mutale Chileshe did her study in Zambia. An additional output of this research would be a comparative report that Dr Virginia Bond will be writing. Although I was familiar with Mbekweni and had made contacts with some local leaders, and as well had the support of the ZAMSTAR team based at Mbekweni clinic, it was necessary to employ a local research assistant, Florence Njila to assist in the field and with some administrative tasks.

1.5 Method of fieldwork

1.5.1 Selection of participants

The study took place in Mbekweni, a peri-urban setting in Paarl District, in the Western Cape. To facilitate the selection of the 10 people infected with TB, I obtained permission to select informants from ZAMSTAR's sputum register of newly diagnosed persons who registered for a secondary outcomes cohort study (SOCS)³. I visited the participants in their homes to introduce the study. During the course of fieldwork, my informants and other people in the community saw me rather as a community health worker than a researcher, since my research assistant was a community based care worker before in the same community. The people with TB and HIV whom I have had contacts with cast me into a position of a government representative and an advisor to their problems about the misuse of disability grant by TB patients. Although these position made consent to participate easy and some people were open about their illnesses, several ethical challenges had surfaced. I was worried that the participants would become impatient with me because of my frequent visits over a period of 6-8 months, especially since I would be discussing food and not providing any food assistance.

However, I referred the families that were in need of assistance to relevant local non-governmental organisations. In the group discussions, my questions about food and the

³ This cohort study aims to measure uptake of TB screening, HIV testing and ART within the trial sites. It also measures poverty and stigma.

way people managed food raised the expectations of some participants that I was a mediator between them and the government, to look at their dissatisfactions with the manner in which local NGOs dealt with food aid.

The initial aim was, after having identified people infected with TB, to understand the impact of TB on families' food security; a family without TB would be located five houses away and to the east of the identified person with TB, in order to learn the variation in the families' livelihoods and coping mechanisms. This criterion proved difficult to achieve since the livelihoods of some families located five houses away were not comparative to families with TB. Because TB symptoms are linked to HIV, a few families refused to be part of the study they said there was no person with TB in their house. As a result, I decided not to mention TB and HIV when explaining the study; instead, I mentioned that I was interested in people's livelihoods and food security.

Ho (2004) states that it is through detailed case study and observation of people going on about their lives that we are able to understand the complex causes and trajectory of diseases. To build a good rapport with my informants, facilitate a more natural interlocation and understand events as they occur I focused on observation and narrative techniques, and kept a field diary. Linda Garro & Cherly Mattingly (1994: 771) state 'narratives provide a powerful means for communicating and giving meaning to experience'. I visited families four to six times over a period of six -8 months of treatment; and I visited the families without TB during the same period to document variations across families over time. I had conversations with the adult woman, the primary care giver, the person with TB, and/or HIV, and the head of the family.

Through the narrative techniques conducted with families affected with TB and HIV I learned about illness experiences during acute and recovery phases. Therapeutic options, reasons for moving between Mbekweni and Eastern Cape during illness period, the direct and indirect cost of caring for the sick, kinship ties and allocation of resources provided insight into the manner people manage illness.

I aimed to understand how kin who lived in the same or at a separate dwelling composition provided care. I established the diversity of social networks, sources of income, asset accumulation, expenditure, and changes as people gradually returned to normal health. In families without TB, I asked about the same themes except not about TB, I found that people experienced a range of lifestyle diseases and needed medical care. Food security was an important issue, and one family had a child with HIV. As a participant observer interested in people's experiences of TB and HIV, and working in settings with minimal privacy with women living with HIV who kept their HIV status from their family, children and some neighbours, and for one woman who kept her TB illness from her children, I had to be careful of who was around. I realised that at other times because of the secrecy around HIV, I also found myself whispering when talking about their experiences of having HIV, although there were no other family members from which the HIV status was kept or visitors. While Elizabeth Mills (2004) found that some people used hand signals and metaphors to communicate HIV positive status, for instance in a group of three people, two people can use three fingers or make a sign of a cross or use terms like 4X4 to indicate that the third person has HIV.

As people began to feel better and moved around their surroundings, did chores, interacted with acquaintances and changed residence, I found out more about other people's lives and their perceptions of their community. When it was awkward to take notes in the field, I reflected on the events and observations once I was back in the site office, and I recorded the notes. In the course of field work I visited the local markets, Max Supermarket in Mbekweni, fruit and vegetable stalls in front of Max, open stalls on grant payout days, at Shoprite supermarket, in a recently opened Mbekweni shopping centre, to see the types of food that were available, pricing, quantity and the types of food people were buying.

1.5.2 Getting to know the community

Before I immersed myself into the lives of my interlocutors, I conducted six focus groups with local key informants. Two group discussions of elderly men and women discussed

timelines of food economy trends, food availability, accessibility and affordability, income sources, changes in food economy over a 10-year period and food particular for people with TB. The first group was held at ZAMSTAR site office in Mbekweni with eight (three men and five women) participants from different sections of Mbekweni. The second group discussion of twelve participants (five men and seven women) who attended a support group for the elderly occurred at the Dutch Reformed Church. Two other group discussions with women looked at seasonal variations of income sources, expenditure, employment opportunities, cash activities, morbidity and mortality. Ten women came from a women's sewing project and the discussion took place in their workplace at Mbekweni Old Library, and six women came from another women's sewing project and that discussion took place at their offices. Eight volunteer members for the Phola Park Peace Committee and eight people (four men and four women) from Phola Park Garden Project took part in the wealth and well-being ranking of the community. I aimed to establish local concepts of wealth, poverty, well-being and vulnerability.

The group discussions provided details about aspects of vulnerability to ill health, namely unemployment, food insecurity, crime, violence, alcohol and drug abuse, limited safety networks, poor living conditions, and marginalisation. Key informant narratives show entangled individual livelihoods and the wider community, in economic and political changes before and after the democratic transition of 1994. TB, HIV/AIDS illness and deaths mostly among the youth, and lifestyle diseases, doubly impoverishes the community. I will discuss these themes in detail in chapter four.

1.6 Chapter Outline

Chapter One: Prevalence of TB and HIV: Contested Terrains

I introduce the study by outlining the background context of TB and HIV and present the case study to discuss the human experiences of TB illness and the strategies that people used to attain good health. The argument counters the prevailing assertions that cultural and behavioural models provide a better understanding of the high incidence of TB and HIV among Africans. I draw on different theoretical lenses that aim to explain the

challenges thrown up by the emergence and re-emergence of TB among the poorer sections of the population in developed worlds and its persistence in under-developed worlds, and the intersecting aetiology of TB and HIV epidemics. A few epidemiological findings which link the contribution of good nutrition to treatment outcomes provides a framework to test the study hypothesis that, 'poor families have a limited capacity to cope with the convergence of TB, HIV and food insecurity without external welfare support'. I suggest that anthropological methods have broadened the epidemiological approaches by bringing out the nuanced livelihoods and strategies used by people affected by TB, HIV and food insecurity.

Chapter Two: Igazi alilihlanga: The spoilt blood that needs nourishment

This chapter gives a thick description of the theme I used for the title of this thesis: 'The spoilt blood that needs nourishment'. Through the narratives and observations of the four women and six men, and their families whose lives have been affected by TB and HIV illness, I was able to understand peoples' perceptions of good health and illness through the use of metaphor [Igazi alilihlanga: spoilt blood], and the needs of the blood to maintain good health. The case studies highlight various social aspects of managing TB and HIV illness that are closely linked to the discussion in chapter three, such as direct and indirect costs, experiences of testing and disclosure, relations with significant others, loss of earnings, treatment seeking and adherence, experiences of TB and ARV medication.

Chapter Three: Support Networks

The argument in this chapter exposes the embodiment of disease inequality and limited access to social networks to restore good health. My analysis of the ethnography draws from Margaret Lock and Nancy Scheper-Hughes three bodies' framework: the individual body, the social body and the body politic, in order to interpret the experiences and responses to TB and HIV illness at individual, community, and institutional levels. The chapter describes how families used their networks amongst close kin, local NGOs and the state, and the way in which families deploy resources. Nine of the ten families relied on their social grants to meet the needs of the sick. In this chapter, I highlight the

shortcomings of the notion of social capital and the one-dimensional definition of a household as emphasised in developmental and epidemiological studies that suggest that the concentration of social networks help the poor to weather ill health and strengthens livelihood strategies.

Chapter Four- Mbekweni: ‘a place of respect’

This chapter traces the wider context of vulnerability through the livelihoods of the ten families without TB. The purpose of comparing families with TB and those without TB, living in the same livelihood zone, was to understand whether the presence of TB and HIV pushes families deeper into poverty. The chapter suggests the historical and political economic context provides a better understanding of individual experiences of ill health and vulnerability to disease. This study found that families without TB were experiencing other illnesses; and social ills as those experienced by families affected with TB and HIV, namely unemployment, food insecurity, poor housing, drug and alcohol abuse, crime, violence and gender inequalities.

Chapter Five: Conclusions and recommendations

Families were temporarily economically drained by interrupted livelihoods as some people stopped working when ill; paid for private doctors and special transport seeking diagnosis and cure; some paid for healing rituals; and ‘special’ foods. External welfare support from the state and non-governmental organisations, and support from close kin was crucial in improving the health of people with TB and HIV, in the face of negligent sources of income such as seasonal wage labour in the agricultural and construction industry, and domestic work. The study recommends that clinics and non-governmental organisations forge strong links to deal with the food needs of people during TB and HIV illness, as not all people received food aid when they needed it. It also recommends a better integration of TB and HIV/AIDS treatment support, as well as empowerment on stigma related issues.

The study recommends the development of guidelines to work closely with traditional healers so that they refer people with TB symptoms promptly to health care centres, as

HIV/AIDS programs initiated that process. Coordination and communication between diagnostic centres for a quick follow of smear positives samples is also important. Intervention efforts also need to consider structural problems, namely crime, violence, gender inequality, alcohol and drug abuse, job creation and housing.

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CHAPTER TWO

IGAZI ALILIHLLANGA

(The spoilt blood that needs nourishment)

2.1 Introduction

Health workers often emphasise the completion of treatment and the need to take medication with foods rich in protein and carbohydrates, however many families managed to obtain basic foods, locally referred to as a 'hamper'. The hamper consists of 10-kilogram bag of maize meal, flour; samp, beans, sugar and 2litre cooking oil, but were often struggling to obtain 'foods that nourish the blood'.

George Marcus (1995) states:

'When the thing traced is within the realm of discourse and modes of thought, then their circulation of signs, symbols and metaphors guides the design of ethnography'(George Marcus, 1995). Spradley's (1979) domain analysis strategy urges us to allow the semantic relationships raised by the informants to guide the integration of findings into theme: in this case, Igazi alilihllanga-the spoilt blood. This theme embodies people's experiences of illness, meanings and values attached to the actions taken to nurture the body from being a symbol of 'blood spoilt by disease' to a symbol of health. The ethnographic data reveals how TB and HIV traverse the bodily spaces between social, economic and political spheres. Hence, the discussion of the findings adopts Margaret Lock and Nancy Scheper- Hughes (1987) three-body analytical framework: the body self, the body social and the body politic. The relationship between these three bodies is, the body self reflects on individual experiences of being part of or being different from other bodies. The social body thinks and positions itself within natural, cultural and societal milieu. The body self and social are fashioned into a body politic that is controlled and regulated by social forces. Therefore, the main argument is that the 'body' in health and the body in sickness represent the position of individual bodies in relation to the larger social order.

This framework provides a multi level understanding and analysis of the embodiment of diseases, and justifies the interpretive perspective of individual experiences of illness and diseases and a critical perspective of the social context in which the affliction is experienced.

TB and HIV/AIDS are material substances, but once they entered the body, they have serious physical consequences (Farmer, 2000). The first part of this chapter presents a profile of the ten informants and their case studies, which I shall number 1 to 10. These case studies show the direct and indirect costs involved in overlapping systems of care from within and across kin and other resources. The families moved between biomedicine, traditional, and faith healing practices. The physical impact, increased hunger associated with medication, lost earnings, fear of disease stigmatisation, burden of caring for the sick, anxiety over imminent death and funeral costs, demands for special foods, limited resources and social networks, disability grants as a resource and a source of conflict, were experienced by all the families.

The second part is an analysis of themes and argues that the context in which TB and HIV illness occurs is crucial to understand as the case material revealed that socio-economic factors contributed to the management of these diseases in Mbekweni rather than socio-cultural beliefs as reported by some studies of TB and HIV illness in South Africa. For example De Villiers- Herselman, (1991, 2002, 2007) explored the perceptions of TB among patients who were admitted in a provincial hospital in the Eastern Cape. She concludes that ideas of witchcraft causation which form part of the Xhosa tradition, and preference for a traditional healer delayed treatment seeking and non-adherence to TB medication. She argues that those patients who believed in witchcraft and yet attend a clinic, hospital or consult a doctor may just be buying time to relieve symptoms while they do not have money for a traditional healer, but would ultimately go to a healer.

In a similar study by Edginton et al, (2002) they found that in a rural village in the Limpopo Province many respondents reported two types of TB, a medical condition and the other was believed to be caused by immoral sexual behaviour. Respondent reported

to have first consulted a traditional healer. The authors conclude that patients may delay diagnosis and treatment at health care facilities. Therefore, the authors recommended that health workers in that village develop a knowledge and understanding of local beliefs and perceptions about illness, and educate patients on medication adherence.

Peltzer & Promtussananon (2005) explored public perceptions of the causes, ways to reduce risk and options to treat TB in a semi-rural area in the Limpopo Province. Findings show that people had limited knowledge and understanding of tuberculosis, the authors therefore recommend health workers provide the corrective education to the rural population. Meijer-Weitz et al, (2001) conducted a study of sexually transmitted infections and condom use among a group of Xhosa and Zulu women who attended STD clinics in Cape Town and in rural Mpumalanga, respectively. Through women's narratives, the study found that condom use was not attractive to both men and women. Because of gender construction, that influences perceptions about male dominance, sexuality and fertility, Xhosa and Zulu women have to submit to the sexual needs of their partners in marriage and out of marriage. While the authors acknowledge that the women who participated in the study belonged to the low-socio-economic group and depended on their male partners for economic support, they recommend that intervention programs that promote safe sex should take into account that non-condom use is not an 'individual fault' but a cultural norm among the groups under study. Liddel et al (2005) agrees with Meyer-Weitz's proposition for social science research to recognise cultural representations of diseases and decision making about safe sex in African communities in the Sub-Saharan. The studies discussed above demonstrate what Farmer (1999) calls 'persistent insularity' among social scientists that are unwilling to learn from the basics of infectious disease or epidemiology, which emphasise the recognition of the context of risk for the transmission of TB and HIV/AIDS.

2.2 Case studies

Table 1: Profiles of people with TB and HIV

	Sex and age	Length of time to diagnose TB	TB outcome	Primary Caregiver	HIV Status	ART
1	46-year-old woman	3 months	Cured	Self and daughters	LWH	On ART
2	31-year-old woman	9 months	Cured	Mother	LWH	On ART
3	24-year-old man	1 week	Completed, still coughing	Sister	HIV-negative	n/a
4	36-year-old man	2 weeks	Completed, still coughing	Girlfriend	Unknown	n/a
5	61-year-old man	Never clear	Re-treated (relapse)	Sister and girlfriend	HIV-negative	n/a
6	50-year-old man	1 week	Completed, still coughing	Mother	LWH	On ART
7	39-year-old woman	18 months	Completed, still coughing	Sisters and Father	LWH	On ART
8	50-year-old man	1 month	Died	Sister in law and Sister	HIV-negative	n/a
9	30-year-old man	1 month	Cured	Self and Father	HIV-negative	n/a
10	32-year-old woman	1 month	Cured, but later died in 2008	Mother and sister	LWH	On ART

Case Study One

Nofirst is a 46-year-old woman, and head of the family. She lives with her daughters Keke (27 years) and Zaza (10 years), Keke's son Alutha (7 years) and her brother Tokwe (57 years) in a brick row house. She learned about her HIV in 2002. Her brother is also living with HIV and he received a grant although his contribution to the family is unreliable and small. After learning about her status, she took her younger daughter Zaza to the clinic for an HIV test that was negative, although Zaza's Tuberculin Skin Test showed that she had TB infection and she received prophylaxis. In 2005 Nofirst noticed that she was losing weight and when she went for her routine examination for HIV at Paarl East hospital, the doctors were concerned about her weight. She insisted on having a test for TB but the doctors were reluctant. When she finally received an X-ray in August 2006, the results were negative. She ultimately found out about her TB in October at Mbekweni clinic. She had a relapse TB and was on treatment for 8 months. When I first visited her in October 2006, she had been on ARVs for 15 months. She has gone public about her HIV status and she is an active member of the Treatment Action Campaign. She had cared for herself and her daughters have supported her during her illness. The daughters often remind her to take her TB and ARV medication at specific times. Nofirst is unemployed, following her retrenchment from Laangerberg canning fruit factory in 1999. She derives her income from a disability grant⁴ based on her HIV status since 2002, rental income (R160) from shack dwellers in her yard, a child grant for Zaza, and sporadic income from beadwork for people living with HIV. Nofirst said she did not crave special foods but her appetite has increased since she started taking TB medication. The ARV clinic staff instructed her not to eat fried foods. At first, she cooked her meals separately and her elder daughter discouraged her from eating different meals and said they were going to eat the same foods as Nofirst. The family managed to have enough food all the time. Nofirst also received food aid from the support group for PLWH.

⁴ The amount for old age and disability grant was R890 in 2006, and child support grant R190

Case Study Two

Bulelwa is 31 years old and separated from her husband. She is living with her 51 year old mother Nozibele, her daughter Bonga (12 years), son Thola (9 years) and her mother's sister's daughter Pat (14 years). The family rents a two-room shack. Bulelwa started coughing in December 2005 while on holiday in the Eastern Cape. She came back to Cape Town in January 2006 to resume work on a grape farm. She continued working although she was feeling weak and losing weight until she felt that she had no energy to carry on and left her job in May. She consulted a private doctor four times (paying between R120 and R150 each time), who told her that she might have TB. The doctor referred her to Mbekweni clinic where she learned about her TB and HIV in September, and started TB treatment immediately and ART in November 2006. She also consulted a woman faith healer at St Johns church who told her she had something dirty inside her that is called 'poison' and the woman gave her "holy water". Bulelwa used the water, which gave her diarrhoea; she thought the water was cleansing the dirt inside. When the diarrhoea kept coming back for four weeks, she went to Paarl East hospital and received medication to stop diarrhoea. She went to the Eastern Cape two times during her illness to undergo a ritual that the family believed would improve her health, which cost the family R700 to travel to the Eastern Cape, and R1200 paid for the goat that the family slaughtered and for food. She disclosed her status to her mother and her mother's sister only and insisted that no one else should know about it, even her children. The family did not always have enough food although Nozibele tried to buy the food the clinic staff had told her to buy such as meat, vegetables, cereals, and tinned fish. Bulelwa felt hungry all the time and craved meat. Nozibele worked full time at a fast food restaurant and Bulelwa received disability grant for TB and two child support grants.

Case Study Three

Monakali is a 23-year-old man, living with his 33-year-old sister Nobantu. Nobantu separated from her husband, and she has two daughters, Thulephi (13 years) and Manyiwe (4 years). The family lives in an RDP house, and Monakali sleeps in his shack at the back. Monakali worked on farms and stopped in October 2006 after he collapsed at work and his employer brought him home.

Monakali's illness started with a sore throat, stomachache and diarrhoea. Nobantu first advised him to go to a faith healer at St Johns church but he found that many people who were seeking help and he did not wait for his turn. He went to the clinic for these symptoms and the medication he was given could not help him. In the early days of his illness, his sister let him stay in the house until he was well enough to sleep alone. She encouraged him to go the clinic to test for TB. He went to the clinic and found out about he had TB in October, a week after he gave in his sputum. He was on treatment for six months.

His use of alcohol during illness interfered with his medication. Monakali received a disability grant. He finished his treatment and went back to work but he was still coughing heavily. He went to the clinic to have his sputum tested again but he never went back for his results, which I was not able to get from the clinic sister until the end of the fieldwork period. Monakali tested for HIV and he said his results were negative. The treatment made him hungry all the time. He craved meat and fish, and the nurses told him to eat banana, apples and peach, and cabbage, spinach, pumpkin and cauliflower. He said Nobantu was able buy these foods but during our visit there was never evidence of these types of food. Nobantu often expressed her frustrations of not being able to have enough food because of other responsibilities and debts. She worked in a private house for three days a week, and earned R900 a month, received two child support grants, shack rental of R160. Monakali earned R240 a week for seasonal work. After fighting with his sister about his misuse of grant, he cooked his food separately in his shack. Nobantu relied on her boyfriend for financial support, which was why she did not want him to know about her HIV positive status, fearing that he would leave her and she would suffer further.

Case Study Four

I met Stanza, a 36-year-old man after he had just moved in to live with his girlfriend Lulu (40 years) in her new one room RDP house; a kitchen cupboard divided the room into a sleeping place and a kitchen. They lived with Lulu's 18-year-old son, Bengo who came from the Eastern Cape to look for work. In October 2006 Stanza noticed that he was

coughing heavily, had night sweats and pains in his body, he then decided to go to Paarl Day hospital and he was referred to Mbekweni clinic. He discovered his TB after two weeks and started his treatment. Stanza said the way he ate had changed since he started taking TB medication. Before, he did not care about food especially when he was busy. Stanza craved meat and understood that he was supposed to eat fruits but at times was unable to get the food he craved because they had no money.

Lulu worked on farms during the harvesting season, and Stanza lived on a negligible income from fixing peoples cars, radios and television sets. His illness prevented him from doing his work and he had no financial contribution for their home. His situation was better when he received the disability grant. Stanza's clinic card showed that he did not take treatment for 20 days between January and early March. He said when he felt better he was just lazy to go to the clinic. He went back to the clinic after the nurses visited him. Although he finished his course of treatment and said his life was back to normal, Lulu said he was still coughing heavily. He stayed in police custody with his friends for stealing goods in Paarl. I saw him after his arrest, when he was going to Eastern Cape for the weekend with his friends. He had to appear in court on two occasions and the case was still on at the end of field visits.

Case Study Five

Fiyo is an elderly man of 61 years; he never married and had no children. His partner, Nombongo is 51 years. They lived in Fiyo's one room shack in an informal settlement. I first met Fiyo in January 2006 at his sister's house. After he found out he had TB, his sister took him into their house to care for him. He was thrown out of the house because he started behaving strangely, waking at midnight, swearing at his sister and her husband, and disturbing neighbours. Fiyo's sister suspected that he had a psychiatric problem. She was concerned about his lack of personal care and hygiene, and his misuse of the grant. At one point, she asked me to intervene to suggest that he allow his niece to manage his grant. Fiyo had consulted a private doctor after he felt chest pains and coughed blood. The doctor referred him for psychiatric observation at Paarl East hospital.

He said there was nothing wrong with him, that maybe the doctor wanted him to benefit from a disability grant although he was already receiving an old age grant. Fiyo also suspected that his partner Nombongo was mentally unstable because she often collected rubbish and piled it in their shack; they sometimes fought over her behaviour. He was into the third month of his six-month treatment when I met him. He finished his first treatment course but he never healed and he was on retreatment for eight months. He tested for HIV and the results were negative. Nombongo cared for him and home based care workers often visited to see that he had taken his TB medication. It was not easy to understand Fiyo's history of TB but Nombongo told me that the previous year Fiyo stayed at Sonstraal hospital, a TB hospital in Paarl. Fiyo however said that he did not have TB then, that he had swollen feet and stomach cramps. It was also difficult to trace his eating patterns and spending because his niece collected his grant and bought food for him. He said he never ran out of food until the next grant payout.

Case Study Six

Early in December 2006, Moya (50 year, man) started feeling dizzy and weak while working on a grape farm and his employer brought him home. He lived in his shack at the back of the family house. His mother Mamthi noticed that he was always in bed, but did not know that his condition was serious. He brought him dinner in his shack; she noticed that he had not been outside for a few days. When she went to ensure he was inside, she noticed that he had not eaten the food they offered him, his eyes looked worn out, and he complained about painful legs. Mamthi encouraged him to go to the clinic; he received tablets for appetite. The nurses told him to bring the sputum jar the following day and wait for the results. His conditions got worse while he was waiting for the sputum results, and he insisted on going to the day hospital. He went for an X-ray and it showed TB. He stayed in hospital for four weeks and went home in January 2007. He started his TB treatment at the hospital and continued to receive it at Mbekweni clinic. Moya also used an herbal mixture to cause him diarrhoea to purify his body. He told me about his HIV status on our second meeting. Apparently, Moya knew about his HIV at the same time he found out about his TB because he started taking ART towards end of January. He ate more frequently than before having TB and taking medication.

He liked apples, melon, grapes, and the milk shake he received from the clinic in his early stages of illness to boost his energy level. The family was struggling to meet their dietary needs although they consolidated their income. This was a family of 11 members including Moya, his mother (74 years), 2 sisters (Fezi 39 and Lola 35 years), 2 brothers (Qongile 37 and Mandla 31 years), 5 of his sisters' children (Sisana 20 yrs, woman; boys: Ndanele 14, Zola 16, Lizo 5 and Sisana's 2 month old child). Moya finished his TB treatment although he defaulted on his ARV treatment. He went back to farm work, still experiencing painful legs and coughing. He never received a disability grant because his identity document went missing while he was in hospital.

He attended a support group briefly at Catholic Welfare Development and received food aid; he also received a mattress from Caring Network Home based Care. Mamthi received an old age grant, the daughters did seasonal work and one of them later found work in a bakery, earning between R1000 and R1800 depending on hours worked. Qongile was on a disability grant for his asthma, and a diagnosed psychiatric problem, and he heard about his TB towards the end of the study. There were two tenants, each paying R70 for shack space.

Case Study Seven

Rainy is a 39-year-old mother of 3 boys. She was married and separated from her husband who is not the father of her children. Rainy had TB in 2002 and finished her treatment regimen. She became unwell again in June 2005; she started by having a runny tummy, vomiting, chest pains. At the time, her relationship with her estranged husband had broken down and he chased her out of the house. She stayed with a friend in the same area and her family heard that she was ill and they fetched her. She went to the clinic and received pain tablets that gave her temporary relief. A woman from the neighbourhood advised Rainy to drink bicarbonate of soda and vinegar to be able to vomit but that caused her heartburn. When the pain persisted, she went to the clinic and gave sputum four times but the result showed no TB. She went to the clinic and the nurses told her she had gastro enteritis. She asked for an injection and blood test and the nurses asked why she was saying that because they did not think it could be HIV.

She then spoke to the community health workers at CWD about her symptoms. The health worker made an appointment for her to see a doctor at Paarl East Hospital. She went for an X-ray and there were no TB spots. She tested for HIV and the results were positive, her CD4 count was 41 and the doctor recommended ARVs. She started ARVs in June 2006. However, travelling to the Eastern Cape for a funeral and staying for a month raising transport money to return to Cape Town, interrupted her treatment course. When she went back to the hospital, the nurses told her to start anew. She was at the same time feeling pains on the right hand side, could not lie still on one side and she was coughing. She went to the hospital repeatedly for tests and CD4 count which was at 21. Rainy also received an X-ray and she heard that she had 'water in the lung on the right side'. She then asked for clarifications and the doctors told her she had TB. A doctor referred to Luthando Care Centre where she stayed for almost two months and came back home early in January 2007. She started her TB treatment and the health workers informed that she would restart her ART at 2 months of TB treatment. She was experiencing body pains, weakness in the legs and skin rash, which she suspected, were the side effects of the injection. Rainy was open about her TB and HIV illness to her family and friends, although when her elder sister was drunk she often ridiculed her.

The family shares a two-room house that has a kitchen and a bedroom. At first there were eight people living in the house: Sam, her 83-year-old father who was disabled, wheelchair bound and chronically ill, eventually died in August 2007. Rainy lives with her two sons (Sizwe 18 and Thando 14). The 17-year-old son lives with Rainy's aunt in Nyanga. Loza (29) and Phiwe (22) are Rainy's sisters' daughters. Loza's mother has her own house in Mbekweni, and Phiwe's mother lived in the Eastern Cape. Lulu (8) and Bhaki (4) are Loza's children. Loza left the household to live with her boyfriend and later went to her mother's place after she learned about her TB.

The family relied on Sam's disability grant of R890. The additional income was a child support grant for Lulu and Bhaki that was R380, and a rental of R50. Later on, she received an additional rental of R50.

Thando's child support grant of (R190) stopped and reinstated in March 2007. Rainy

also received her disability grant of R890. The family often had not enough food; Rainy worried more about the children saying that she was older and could sustain hunger. She said she does not have energy anymore to go and work on the farms; she stopped working because of sickness. She sometimes borrows between R100 and R200 to buy food, and her boyfriend helped most of the time. She said her children worry too about her when there is no food because she needs to take her medication with food. There were times when the family battled over the little food that was available. They received food aid once in December from CWD but it was not enough for the family.

Rainy's sister's son, Xola, who went to the Eastern Cape for initiation early in the year and came back in the middle of the year. The older sister Nora (Xola and Phiwe's mother) came from the Eastern Cape for her father's funeral and decided to stay as she was waiting for an RDP house in Mbekweni. Sam used to sleep alone in the bedroom and the rest of the family slept in the kitchen area. After Sam died the beds that were in the kitchen moved into the bedroom, and there were four beds in the bedroom, so all the family members slept in one place. The family's financial circumstances worsened after Sam's death and the money that he saved in the bank covered his funeral costs. They then had to live on Rainy's grant, and the additional members in the household have put a strain on the household's resources as Rainy complained that her older sister Nora was not contributing financially and her son contributes only R50 a month. At times Rainy struggled to raise transport money for routine checkups at Paarl East Hospital. She once walked more than 5 km, to the hospital, and on another occasion asked a doctor for a taxi fare.

Case Study Eight

Speech was 50 years old and worked for a construction company in Wellington for seven years. He did not have any children and was not married. He lived and cooked separately in his shack at the back of his older brother's house (Mehlo, 57 years). Speech looked forward to a Christmas break to enjoy with family and friends in the Eastern Cape, and to go back to work in January 2007.

However, his health prevented him from fulfilling his plans. He started losing appetite and weight, and had no energy to do anything. Misiwe (43 years), Mehlo's wife, said they noticed that Speech was sick when he came into the house to watch television and they offered him food but he did not eat. As a result, they let him eat inside with them because he was too weak to care for himself.

He decided to see a private doctor just after Christmas. The doctor referred him to Paarl East hospital and his appointment was on the 8th the same day he was supposed to go back to work. He was worried about not being at work and asked the doctor to give him an injection and the doctor said the injection was not good for him at that stage. The doctor gave him some tablets to take until the 8th. On the 8th, he went to Paarl East hospital and received an X-ray, which showed that he had TB.

When he asked for a medical certificate at Paarl East, a doctor told that he could not go back to work because of his health. He was very weak when I first met him and he had just started his treatment for TB. He was not talking much and always inside watching television. Speech continued to lose appetite, weight, energy; and coughing, and experienced dehydration although he was taking his treatment. At times, he tried to do chores although his family stopped him and said that he must look after his health. He felt unproductive and felt like a 'dead person'.

Misiwe looked after him and she asked her sister in law (Speech's sister) Dabs, who lives in another section in Mbekweni to come to the house and look after Speech while Misiwe was at work. Speech liked pap-crumbled maize meal porridge, and maas- sour milk. His sister Dabs ensured that Speech ate his breakfast before he went to the clinic, as it was essential for his recovery. Dab's daughter had TB in 1997 and the medication made her weak too. Thus, Dabs knew what to give to Speech: she said eggs and soup were good for nausea and that fat was not good for someone with TB.

Misiwe wanted to take him to a private doctor for examination but had no money at that stage. She went to Mbekweni clinic and asked the sister in charge for Speech's medical

report. The sister in charge referred to Paarl East hospital where Speech found out about his TB. She also wanted to take the medical report to Speech's former employer. The Mbekweni clinic referred Speech to Sonstraal hospital in April as his condition worsened. Misiwe, at that time was helping Speech to apply for a social grant. When Mehlo visited him in hospital, he did not look good and did not eat the fruits Mehlo had brought him. Unfortunately, Speech died later that day. The funeral happened in the Eastern Cape. The family felt emotionally drained. Mehlo's sugar level went up and he stayed in hospital before he went to the funeral while Misiwe had to go to the Eastern Cape for the funeral preparations. Speech did not have a funeral plan, however the family consolidated their resources and the funeral costs were covered. Mehlo used his wages, and sold his two old cars that had been standing in the yard for some time. Speech's employer donated R800 and his sister used her car and hired a trailer to transport the body. His sister Sisana also got donations from her church.

Mehlo had planned to go back to Eastern Cape in June for the washing of spades-a ritual, instead Misiwe went because she and her son Sese (14) who had a good relationship with Speech, had dreamt about Speech sitting in the lounge. Misiwe could not ignore this vision and she went down to perform the ritual. The family said they would also complete building his house and their elder daughter would use the shack he used to live in. Misiwe said they also learned from Speech's employer that he invested some funds and Misiwe's children were beneficiaries. I left the family trying to get those funds. They also recovered financially and managed to buy another second hand car from Misiwe's informal savings plan and Mehlo's income from full time employment in a construction company.

Case Study Nine

(The introductory chapter opened with a vignette from Xozza's case study). When I first visited the family in the hostel, they occupied three small separate rooms. Xozza shared a room with Mzala (40), his mother's brother's son.

Malangeni slept in the other room and his brother Soso (23) and two younger sisters Nodovu, (10). His sister's daughter, Nomase (6), slept in another room, which was also a

kitchen. Xozza was alone in the house most of the time because Malangenii was at work and the children at school. When he was too weak to get out of bed and help himself, his father cooked his meals before leaving for work. His elder brother who lives about 10 km from Mbekweni went around often seeing him. He said there were times he wanted to get something that was out of his reach and there was no one to ask, so he would give up and stay in bed. The physical inability to do things frustrated him.

Xozza had no special food demands; he ate like everybody in the house, although in the first stages of illness he craved meat. His father said they normally took meat on credit from a local hawker, even before Xozza fell ill. Malangenii bought food in bulk for a month and additional foods in the course of the month. Xozza received a disability grant of R890; he first received a lump sum of R3430 for 4 payments. He saved R2000 in the bank for emergencies; he bought himself clothes, sent money to his mother, bought food for the family, and kept some for pocket money. Xozza was anxious to go back to work and did not like to depend on his father for survival.

He said, “It is not nice to depend on someone when you are not sick, depending on someone can make life difficult”. Xozza drinks and smokes tobacco. He only stopped when he was very ill and resumed after he completed his treatment. Xozza found a job at a hardware store and earns between R800 and R1800 a month depending on the hours worked. He used his traditional medicines at times to protect himself from evil spirits. In my last visit, the family stayed temporarily in a nearby hostel while renovations took place in their family unit. Those who had lived in the hostel the longest were the beneficiaries of the new family units. The place they moved into was a one-room house made of steel. The floor was not covered; there were four beds in the single room, and a bar fridge, kitchen utensils, and clothes were hung on the wall. Seven people shared the room.

Case Study Ten

Beshela (32) got married in 1992 at the age of 17 but the marriage fell apart due to husband's heavy drinking and abusive behaviour. She is living with her 71 year old mother (Gaba), 66 year old father (Kwaito), her two sons 9 and 7 years, and three other children: 10 and 11 year old girls and their brother 15 years old. Their mother and grandparents have died. Their grandfather was Kwaito's brother. The family lived in a hostel before and acquired a one room RDP in which they live now. Beshela was working on farms and stopped in October 2006 when she felt that her body was weak. Beshela started losing appetite, which resulted in her weight and energy to drop to an extent that she was unable to move out of bed for some time.

Seeing that she was not eating and continued to be weak, her mother Gaba took her to a private doctor. Although Beshela said, she did not have any symptoms or pains she was just losing weight, Gaba said Beshela had short breath and chest pains. The doctor referred her to Paarl East hospital, and she heard about her TB and HIV in November. She was referred to Luthando care centre but she refused to go and went back home. Her health deteriorated and she consulted a doctor again and the doctor referred her to the General Hospital where she stayed for more than a month. She said she started coughing and having night sweats while in hospital. She was on 8 months treatment.

Beshela told her mother, sister and her boyfriend about her HIV status and a few women who became close to her, as they were also HIV positive. Her boyfriend promised to go for a test but Beshela did not know if he subsequently had the test. When she saw him later, he said he would not go for that nonsense. Beshela suspects that she got the virus from another man. Beshela keeps her status from the community, as she feared ridicule. When people are drunk they tend to speak unpleasantly of HIV positive people. She started on ART in June 2007 and had experienced some side effects such as skin itching, rash, drowsiness and blurred vision. Beshela stayed in hospital again for 7 days and had an operation on her spine. She said the doctors drew two litres of water and blood from her back. I saw her two weeks after she came back from hospital. This time her sister (Thethiswa) cared for Beshela in her house.

Her mother said she wanted Beshela to get better before moving back home. Gaba came to Thethiswa's house to look after Beshela during the day, while Thethiswa went to work on farms.

She started receiving the disability grant in May and decided to fetch her eldest child from her in laws in the Eastern Cape. She had last seen the child when he was 2 years old. Beshela's trip to the Eastern Cape did not turn out so well, as she found that the child lives with relatives elsewhere. She wanted the child to know that she was now sick, a topic that elicited emotions as she tried to hold tears back. She felt guilty that she might die and leave the child without ever knowing who the mother was. Culprits had robbed her of her wallet that had R600 and her ARV medication. She blamed the ARV medication for making her sleepy and loose awareness of the fact that robbers preyed on her.

The family survives mainly on welfare grants of R2160 a month (excluding Kwaito's because he does not contribute to the household expenses) for Gaba's old age, Beshela's disability and child support. One of my visits fell on the grant payout day. Beshela said that if it were their mother's payday they would be eating meat and drinks and not sitting like orphans. All the adults in the household supplemented their income by doing seasonal farm work. At one stage of Beshela's illness she consulted a doctor but did not have the consultation fee; the doctor kept her identity document as collateral.

Beshela used to eat once or twice a day. She started to eat frequently because of the medication. She preferred bananas, pears, rice and bread, and asked her mother to buy fruit when she longed for it. Gaba borrowed money for these special foods or took chicken on credit and paid it back later with her old age grant. Gaba got frustrated when Beshela was very ill and had no appetite for some foodstuffs that her mother bought. Gaba tried to get most of the foods the doctors have advised her to buy for Beshela. On her grant payout day, Beshela asked her to buy chicken portions, mayonnaise, tomato sauce, aromatics, cabbage, potatoes and drinks.

Gaba has not fully recovered emotionally from the death of her daughter who was murdered by her partner a few years ago. She was very anxious about Beshela's health and not sleeping well because no one in the family had been seriously ill and needed intensive care like Beshela. She said Beshela's illness prevented her from fulfilling her plans, or attending to other needs because she has to care for Beshela. Gaba wanted to go back to the Eastern Cape but could not go because of Beshela's illness. Gaba got anxious about Beshela's condition every time Beshela was out socialising in a shebeen- a liquor outlet and drinking place in the township. Florence recently informed me that Beshela died in June 2008.

2.3 Physical Experiences of TB and HIV illness

Susan Sontag argues that the use of metaphors distorts and devalue the physical experience of the diseases, however I agree with Garro & Mattingly, 1994; Kirmayer, 1992; Peirett, 2003; Scheper-Hughes & Lock, 1987) that metaphors in illness narratives are conveyers of human experiences and cultural representations of images and meanings of sickness and illness. The isiXhosa speaking people believe the nature of the blood one possesses determines optimum health. They regard bad blood as a sign of bodily imbalances and presence of disease, and good blood as an indication of a balanced body and absence of diseases. In the early stages of illness informants experienced a range of symptoms namely, coughing, chest pains, sweating, backache, dizziness, painful feet, loose bowels, loss of weight and appetite for food. They and their families were concerned with the amount of weight the sick had lost. Their descriptions of the physical impact of illness had changed their perceptions of self. Moya described himself as '*crushed and emaciated*', and his mother said TB has '*crippled him*'. When Speech was weak and could not do any tasks, he felt like '*dead*'. Xoza's father said he looked '*polluted and thin like a rod*'. Beshela expressed an overwhelming feeling of co-infection and said the doctor told her that, '*there is no disease that I don't have*'. Their families may also have infused these feelings and thoughts not in a demeaning way but a caring one, mixed with anxiety of losing their loved ones and the burden of funeral costs.

When Beshela was in hospital and reported that the doctor drained two litres of blood from her back, her mother wondered where that amount of blood came from as in her eyes, Beshela had no blood, as her body looked emaciated. At some stage, Speech was feeling too weak, but he tried to be strong and do chores so that he did not look defiled to others around him.

Scheper-Hughes and Lock (1987) argue that body imagery is important in a medical anthropological understanding of peoples' conceptions of body boundaries, while distortions about body imagery are rare, mental anxieties about the body in ancient and contemporary societies, the quality of blood, pulse and circulation are the common primary diagnostic signs of health and illness. The illness narratives suggest no irrational thinking or body distortions about the symptoms as reported by some cultural studies. The symptoms that the informants described are not different from those of biomedical explanations of TB and HIV signs.

The preceding paragraph highlights the 'physical terrain of disease' (Scheper-Hughes and Lock, 1986) which implies not only an individual bodily experience, but also an experience that interfaces with layers of the social structure. Using popular discourse, people infected with HIV referred to their affliction as, *ndinale nto iphandle apha – I have this thing that is common or out there*. While people are aware that TB is widespread in the community, it is rarely referred to as *this thing that is out there*. Although it suggests an awareness of the extent of the desolation the disease cause across the nation, locating HIV/AIDS as *out there*, also implies ideas about a new disease that is hard to control and incurable. As Mvelo, an elderly church leader reflects, *this common disease, this new TB is very hard to control – “iyabaqwenga abantu ifuna ukuba siphathisane singajongi kurhulumente” – it destroys people it needs us to work together and not only look up to the government. We need to work together to fight this disease, it is like the disease that was called pink eye. Many people in Mbekweni know about this disease; it affected a lot of people, some did not have money to see a doctor.*

Likening these common diseases with pink eye⁵ also highlights the notions of new infections and lack of resources to deal with shocks as they occur.

2.4 What causes my illness?

Scheper-Hughes and Lock argue the body is a good symbol and a structure 'to think with'. For instance when illness strikes, the questions that people ask like, what is happening, why me, what can be done? In addition, their answers to those questions reveal their relations with other natural, supernatural and social spaces. This study found that four of the five informants who experienced TB and HIV did not associate their HIV with 'magico religious beliefs'. Several studies of TB and HIV often report that illness representation among Africans constitute proximate and ultimate causes that are sought in witchcraft and therefore only traditional healers can cure the symptoms experienced and determine who sent the misfortune (De Villiers, Peltzer et al, 2005, Liddel et al, 2004, Edginton et al, 2002, Ashforth, 2005). Even Xozza who initially associated his symptoms with sorcery changed his mind after diagnosis and refused to use the herbal mixture that his father bought. His occasional use of traditional medicine brought from Eastern Cape is justified in terms of an evil eye because of competition over scarce material resources (Herselman, 2007). Anthropologists Frederic Le Macis and Rehanna Ebrahim-Vally (2005) found similar views amongst a group of HIV positive women in Limpopo who were dating migrant workers. The women mentioned that although it is perceived that migrants are struggling in cities, the fact that they often go back home with money, or send money to their dependents, are able to build a house, open a small shop and improve social standing of his children, they are still perceived as better off. The migrants thus become the envy of people in the community.

⁵ Inflammation of the conjunctiva, the thin membranes that line the inner surface of the eyelid and cover part of the eyeball. The most obvious symptom is reddening of the affected eye; the eye usually feels gritty and has a runny discharge, which is commonly caused by a viral infection (Guide to medical cures and treatment, 1999:146). A lay understanding of pink eye is that it is transmitted through eye contact with an infected person.

Bulelwa, Moya and Speech thought they got TB by inhaling chemicals, tar, dust, and by exposure to bugs at work without the use of protective clothing. Bulelwa's mother suspected that Bulelwa's co-infection with TB and HIV was due to her susceptible blood as a result of the family's disregard for certain rituals until Bulelwa came of age. Bulelwa confused how TB and HIV are transmitted as she said the counsellor explained to her that these days people do not get HIV through sex, it is an airborne infection, but also said she thinks she got HIV from her boyfriend. Monakali and Stanza associated their TB with smoking dagga and Rainy said she got TB through excessive drinking of alcohol. She said when she was diagnosed the second time the doctor said she drinks too much carbonated drinks, and admitted to me that she was in fact drinking alcohol heavily then. Beshela and Nofirst could not say how they thought they got TB, Nofirst only said she had it before.

While Fiyo also could not say how he got TB, when describing his symptoms, his partner Nombongo related the symptoms to witchcraft. Rainy and Moya suspected that they got HIV from their previous partners as they claim they were promiscuous but Moya agreed that he was also promiscuous. Moya later associated his painful leg to 'ibekelo' - stepping on an evil substance, when he was young, and it came back during his illness. When Beshela's health deteriorated and she was operated on her spine, her sister suspected that Beshela had meningitis since her sister had seen before that people who have had operations on their backs suffered from meningitis. She said Beshela might have meningitis because she may be thinking too much about her illness. Hellman (2007) asserts that external forces such as diet, environment or supernatural agents may influence the goodness of the blood as life sustenance. Although the informants did not describe the causes of TB in strictly biomedical terms of contagion theory, their descriptions suggest the mechanisms often suggested by the social theory, through which their bodies became vulnerable to TB and HIV (Farmer, 1999, Singer, 2000).

2.4.1 Mistrust

Scheper-Hughes & Lock (1987) argue that bodily experiences represent what people think about society. Farmer (1992) and Fassin, (2003) assert that blame, accusation and suspicion have been a prominent part of social discourses worldwide on the origins of HIV/AIDS since the disease emerged in the 1980s. During this period, the rumours spread in Eastern Europe, Latin America and sub-Saharan Africa that AIDS was a plot by United State of America against Third World countries (Fassin, 2003).

Fassin (2003) states that suspicions of HIV/AIDS conspiracy have been pronounced by the media and politicians more in South Africa than in other countries, to an extent that some conservative officials blatantly rejoiced at the prospect of the eradication of Black populations by the epidemic. When Beshela's sister advised her to go to a crusade with a White preacher from overseas to be cured, she refused and said, *'no ways are these Whites not going to bring us diseases?'* Fassin concurs that suspicion such as those held by Beshela should not surprise us as they were confirmed by Dr Wouter Basson, the director of the apartheid government's Chemical and Biological Warfare programme, in his testimony during the Truth and Reconciliation Commission hearings. Dr Death, as the media and some township residents referred to him, mentioned that HIV was among the infectious agents that the officials planned using to reduce the number of Blacks (Fassin, 2003). As Scheper-Hughes and Lock (1987) agree, to conceptualise diseases as only diseases with biological origins is to be sympathetic to the biomedical approach and deny the radical political discourses of 'why me', that is, why diseases affect some sections of the population and not others.

2.4.2 Blaming Others

Mpange, an elderly woman who participated in a group discussion, linked the spread of HIV to the mobility of people from the Eastern Cape to the Western Cape for better medical care. In turn, she explained, people who are sick or who fear stigma in the townships escape to the Eastern Cape and spread the virus there.

Joy said since the arrival of people from Africa, meaning non-South Africans, *there have been many illnesses in our communities*. Another woman countered this view and said, *but what is surprising is that they do not come here looking sick, it is us who give them sicknesses. Have you heard that they get sick because I always see them moving about selling their wares? If you go to the clinic, you will find mostly local people*. Rainy, Moya and Beshela blamed their former partners for giving them HIV and Beshela's partner blamed her.

2.5 Searching for diagnosis and cure

The actions and decision that informants had taken reflect a sense of agency and proactive stance in demanding diagnosis and cure. The onset of physical symptoms presented a complex search for diagnosis as the informants tried different treatment options. Four people went to the clinic, three to private doctors, one to the hospital and two to a traditional healer first for diagnosis. The costs for private doctors were between R100 to R150 for each consultation, private transport cost between R50 to R200 especially during the acute phases since people were fragile and would be uncomfortable in public transport that is cheaper. Some went to doctors outside the Paarl area. Bulelwa said she was reluctant to test for HIV although when she went to the clinic she first told her mother that if the nurses asked her to have a blood test, she would do it and if she had the virus, she would accept it. She eventually decided to have a test and when the result came out positive, the counsellor asked her if she was shocked to hear that she has the virus. Bulelwa said she was not shocked, if she has the virus, nothing else she could do, *'it is there I have to accept it'*. Monakali said he was not worried about his TB diagnosis because he has seen other people who have had TB are healthy. He said he told himself that he will treat TB until he was cured, although on the question of testing for HIV, he said he was scared to find out about his status because he can see that people who are positive lose weight and *'this virus kills'*. Xozza was scared that he might have *'this common disease AIDS'* but his results were negative.

On the other hand, when Rainy and Nofirst experienced symptoms such as diarrhoea, vomiting, and weight loss they demanded to test for TB and HIV. They said it was better to know whether one has 'it' or not.

Nofirst said, *I was telling my daughter that I am losing more and more weight and I do not understand when they are telling me that I do not have TB.* Rainy rejected the nurses' misdiagnosis of gastro enteritis. She explains, *I went to the clinic they said it is gastro and I said there is no gastro like that, for 3 weeks? Moreover, when having gastro I am supposed to be excreting white watery substance but I was excreting the greenish one. I asked for the injection and blood test, they asked why I am saying that because they don't believe that it's HIV, I told them I believe in knowing what I'm sick with. They tested me then I tested HIV positive.*

She also encouraged her current partner to have an HIV test so he could get medication to make him strong. Beshela said, after finding out about her HIV positive status she did not think seriously about it because the counsellor told her to accept. She said the counsellor asked her if she was not going to cry, Beshela said no, *'I could only restrain myself'*. Nofirst said she was also not shocked and she asked the counsellor if there was help for HIV. Then the counsellor showed her the pharmacy at the clinic to get medication to lessen the viral load, and emphasised that the medication does not cure the virus.

The nurses at the clinic told Moya to wait for his results. He was anxious, did not wait, and insisted on going to hospital as he said, *I told my sister that I was going to the hospital now, she said no, and did not the nurses tell you to wait for your results. I said no I am the one who is suffering. Then she agreed to take me to hospital. We took a taxi to the hospital and I received good treatment there, they took me for X-ray. They said I had "ichaphaza leTB" - the TB spots.* He said finding out that he has HIV did not bother him as the doctor told him the medication would protect him from opportunistic infections. He said he was not sure if the medication would cure his HIV.

2.6 Therapeutic options

De Villiers (1991) states that indigenous beliefs of TB imply that biomedicine is ineffective even if used over a long time. This study found that informants completed their treatment and confirmed that it helped them, and those on ARVs continued with their medication. Therefore the findings warn against general theorizing about African indigenous representations of TB and HIV/AIDS illness as explained in witchcraft and sorcery (Liddel et al, 2003) and romanticizing folk healing (Farmer, 1999). Although some informants may have delayed presenting themselves to the health centres on the onset of symptoms, when they did, the system prolonged the diagnosis, as the standard turnaround time is 72 hours. None of the informants received their test results within this period; the closest was five days. These findings justify their repeated visits to private doctors. Undiagnosed TB suspects pose a risk of transmission to those in close contact with them (WHO, 2005).

For instance, Bason et al (2007) reviewed the TB notification register at TC Newman hospital in Paarl, the most used hospital by people from Mbekweni. They found that the period from first visit to starting treatment varied from one day to 452 days with a median of 15 days, and a calculated average of 41.1 days. If the one patient with 452 days was omitted, the recalculated mean is 24.4 days. The authors state that the senior staff at the hospital said the delays from the presentation of symptoms to diagnosis were often unnecessary, and were due to failures by the doctors, patients and laboratory staff⁶.

⁶ Doctors' appointment dates to review results took longer than one week. Doctors failed to check results on follow-up visits or did not understand the purpose of the visit, misdiagnosed patients as having a bacterial lower respiratory tract infection. Patients did not hand in sputum samples, missed appointment dates may be due to transport problems, finance, other family commitments or lack of insight into possible complications of the disease. Some patients avoid diagnosis and treatment to remain sick to qualify for government grants. Some present with atypical or minor symptoms, delay coming back when they do not get better on symptomatic treatment. There was lack of quality control of specimen for example: leakage, unlabelled containers and contaminated contents, couriers and administrative problems, delay in getting results to various clinics. Clerks give patients follow-up dates later than the date requested by the treating doctor, due to clinics being fully booked. (Bason et al, 2007)

Therefore in the presence of symptoms and desperation to get better people were compelled to try alternative therapy.

Nofirst found out about her diagnosis after three months. It took Bulelwa nine months to hear about her TB. She visited St John's apostolic church several times for purging body impurities through induced vomiting, enemas and steaming. However, she stopped when she realised the treatment was too heavy for her condition as the herbs loosed her stomach and drained her. She went to back to hospital. Monakali had visited the clinic several times and when he gave his sputum, he received his results within a week. Before diagnosis, his sister advised him to go St John's church but every time he went, he found the church full of people who needed help and he could not wait for his turn. Xoza learned about his TB after a month when he came back to Cape Town from Eastern Cape. Xoza did not go to St John's for healing although his cousin said it was a good church, and he did not mention that the church could treat TB and HIV illness. Xoza considered using the traditional herbs simultaneously with TB medication as *'killing himself'*. Before diagnosis, a woman advised Rainy to use bicarbonate of soda and vinegar with water. Rainy knew about her TB diagnosis after 18 months. Moya found out after a month; he bought an herbal mixture from a hawker, which he said was for bodily ailments. It took Speech a month, Stanza, two weeks, and Fiyo was never clear about how long it took him to hear his results.

Going to the Eastern Cape is an important journey for many people who live in Cape Town. People perceive this journey to hold the key to some degree of well-balanced health. The experience of dreaming about the living or dead compelled some to consider or perform certain rituals.

A few weeks after Speech's death, his brother Moss was meant to go back to Eastern Cape where Speech was buried, for an isiXhosa custom that is performed a week after the burial- *'ukuhlanjwa kwemihlakulo'* - the washing of the spades that were used for digging the grave. Misiwe had to go for the ritual after she and her son dreamt about Speech, so that the deceased does not bother her again. Bulelwa also dreamt that her

uncle put a traditional necklace on her neck and said Bulelwa could heal. When she relayed the dream to her uncle and mother, the family recalled that they have not done a ritual named 'isiyaca', for Bulelwa. Then the family decided that it was about time that they performed this ritual. To make sure that the ritual goes accordingly Bulelwa went to the Eastern Cape to be with elder kin. Bulelwa's mother fully supported this action although she cast doubt over whether the rituals would cure Bulelwa's illnesses. Nevertheless she was hoping that the ritual would ease her from suffering, as she said, *I am not saying it is the cure for her illness, I am saying maybe she is infected with these illnesses because her blood is weak as a result of not doing rituals for her according to a Xhosa tradition. We might say the doctors are not doing their job well whereas we are also at fault by not doing our Xhosa rituals that we are supposed to do.* I agree with Liddel et al(2003) that it is important to unravel the use of folk healing in the context that it occurs rather than explain it as shaped by ... 'deep-seated beliefs in the powers of indigenous medicine and divination' (De Villiers, 1991, 2000). Folk healing is a pluralist medical practice not an exotic practice of poor ethnic groups, as other privileged people in America and Europe often consult chiropractors, homeopaths, acupuncturist and movement therapy (Spiegel and Boonzaier, 1988).

Three women had not tried other therapies for their HIV, as part of the ARV education that they had received; health workers instructed them not to take ARVs with other medications.

2.6.1 The food that nourishes the blood

Van Helden (2003) argues that the solutions to TB and HIV/AIDS mortality 'have been staring us in the face all along', that is alleviation of poverty and improved nutrition. Food security refers to a country's access to enough food to meet the dietary needs of people, and to people having access all the time to available and adequate food to lead a healthy life (Dept of Agriculture, 2002, Gillespie and Kadiyala, 2005). However, these solutions proved hard to materialise for people living with TB, HIV, or those who may be free of these diseases but experiencing food insecurity. Studies on the direct cost of

illness often report on health care utilisation fees and do not consider the costs of nutritious foods for the sick (McIntyre et al, 2006). The following discussion highlights double impoverishment that families have experienced as a result of TB and HIV illness, food insecurity and the extent to which families tried to meet the needs of the sick while they also have to contend with other family responsibilities. The findings reveal that families managed TB and HIV illness better with improved nutrition. The informants reported increased hunger and craving 'special foods' associated with taking TB and ARV medication, and the need to take pills on a full stomach as many people experience dizziness, vomiting and nausea if they took pills without first eating.

Many people whose bodies had been spoilt and wasted by TB and HIV illness, perceived food as a critical response to 'the needs of the blood' during illness periods. The idea of feeding the body to heal and bring a person back into 'good blood' puts strain on families' limited resources. When informants spoke about the kinds of food they buy, they differentiated the foods that nourished the blood from the foods that do not. Nofirst said *I am eating too much since I started taking the TB tablets*. Moya agreed and said, *I eat a lot now, I can finish two plates of food a day, I eat three meals and even get up at midnight and eat,... yes when I feel hungry I wake up and search for food, my family knows that there must be some food left in the pot*.

People demanded eggs, cereals, fruits, meat, dairy products, vegetables that were not always part of their diet. The families tried their best to provide the foods that nourished the blood to regain health; they felt burdened sometimes, as these kinds of food were not always available in the house, forcing families to borrow money or food.

Beshela's mother said, *even this morning, I went to borrow R50.00 to buy the drinks that she takes, bananas and apples. I am buying these things, because the nurses said she should be taking them. But I see that she does not like apples, she has just cut one half and the other she gave it to the kids, I said to her, wowu![exclaimed] you are wasting my money*. She sometimes went to a community garden to pick *imifino*- wild greens that she mixed with maize meal or maize rice for sustenance. Bulelwa's mother said *Bulelwa*

must see what food is available in the house. She cannot expect to eat nice food all the time.

Seven of the ten families were often struggling to obtain food. Nobantu, Rainy, Stanza and Moya's families were experiencing food shortage more than others were. For instance, Stanza could not get the foods he craved. When asked to recall the food they had eaten in four days, he recorded the following foods, Day 1- brown bread and potato soup, Day 2- bread and offal, Day 3- samp and peas, and Day 4- pap (thick maize porridge) and meat; it was before he received his grant. Nobantu said when she does not have money she tries at least to get eggs for Monakali because he is sick and the children are not sick. In Rainy's house, food was a big challenge, she said their biggest worry was obtaining food and she worries more about not feeding her children enough, she said

I also lack a lot because even my father's grant is not enough, it's no money, look now the small one was looking for porridge, there's no sugar, no maize- meal, there's nothing we only have maize, they know that when foodstuffs are still available we cook porridge they eat it before leaving for school usually I don't even have bread money. Sometimes we cook samp, they eat it when going to school, and that becomes their meal for the day. I am not right; I always think of what are my children going to eat. Now that makes me sick, it causes me stress.

Rainy recalled that over four days they ate the following foods- Day 1: they had morvite (wheat energy porridge), bread, samp and rice with no accompaniments. Day 2- bread and morvite, Day 3- pap and meat, bread, samp & potatoes and Day 5-rice, pap, samp, maize porridge and milk. After her father died, the shortage of food in the household worsened, and sometimes she would ask her neighbours for some food like igwinya-vetkoek (a piece of fried bread), to take her TB medication with.

Moya's mother lamented, *what is worrying is not having money, money slips through our hands. It is not nice when the food gets finished because I must go out and bother people. Not only because he is sick, you worry because children don't have jobs and they depend on my grant, do you understand, I could have fixed this floor long ago, it's worse with the*

young ones they always call on me and want food, 'Mamthi ukutya' [Mamthi- food] and I say 'yho' - [deep sigh]

Participants in the focus group discussion reported that families need nutritious food during illness as the elderly woman said, *TB is caused by the lack of food, and that many people cannot afford vegetables, fruits, we even struggle to get eggs for our children to an extent that all our children have TB, they all have TB due to malnutrition.* Another elderly man confirms that sicknesses do make a person poor because people spent most of their money on medical care and people live with *nothing to cook... the people who have TB in this community do need help because they must get food such as vegetables and those foods are scarce, so people are eating dry foods.* Another elderly woman whose daughter has had TB said she tried to give her daughter all the foods that *were going to be compatible with the needs of her blood,* such as tomatoes, cucumbers and spinach. She said it was not good to eat much maize meal as it makes people sick.

Figure 1: Family Meals

In these pictures are the types of foods that the families ate over four days from Thursday to Sunday. Many informants mentioned that meat is a relish often reserved for a Sunday meal. Many families rarely ate vegetables as can be seen in these photographs.



Comparative 6 in a brick house: Manabe and a tenant eating samp and beans, pap and chicken



Comparative -9 in a hostel: samp and beans, pap and chicken, Bread, Manze porridge, Rice and chicken



Comparative-2 in a shack: samp and beans, maize porridge



Monakali's place in an RDP house, black tea and bread, pap and meat, rice and potatoes



Rwinyi's place in hostel, rice and tsotso, pap and chicken



Bulelwa wearing 'tsiyana' traditional necklace after a ceremony in EC, lives in a shack, eating rice, soup, chicken, rice and minced meat



Comparative 5 in a brick house- bread, tomato and tea, milk and sweetbix cereal, rice, chicken, potatoes



Speech in a former hostel, died 4 months in treatment, eating rice, potatoes, beetroot and chicken

2.6.2 Not my normal body size: Implications for TB, HIV disclosure and Stigma.

In many African communities in South Africa, people are conscious about a fat and a thin body as the manifestation of the presence or absence of diseases especially in this era of TB and HIV/AIDS (Mvalo-Matoti, 2006). All the informants began to move around their community after two months in treatment, when they gradually put on weight. For some informants the benefits of putting on weight were twofold, firstly to indicate recovery to good health, and secondly to dispel any suspicions of HIV/AIDS illness. Moreover, if HIV positive, informants had to grapple with issues of disclosure and stigmatization.

Being part of social networks and having a life disrupted by a discrediting health condition means that people have to devise mechanisms to reconstruct mind, body and self to fit in the social structure or succumb to feelings of being discredited by

disengaging from the social networks. Goffman (1963:3) argues that society casts persons into categories and identities that determine normal or abnormal behaviour or attributes. Stigmatising refers to an assigned attribute that makes people different from others in the category they belong. He defines stigma as a deeply discrediting attribute and emphasised that stigma should be viewed in terms of relationships rather than personal discrediting traits.

In the third month of her treatment, Bulelwa's mother could see that Bulelwa was looking better, but *she has not returned to her normal body*. As a result, when Bulelwa wanted to go back to work and insisted that, *I could feel now in my body I am no longer weak I am fresh*, her mother discouraged her and said Bulelwa must recover fully. When I visited Speech the third time, his caregiver asked if I noticed any difference in Speech's condition and I said, to me he was looking a little better than the first time I saw him. She shook her head in disagreement and said Speech was still coughing, has no appetite and not gaining weight. Beshela wanted to attend a burial society meeting and her sister discouraged her because she looked frail and people would easily notice. Beshela agreed and said, *no not now, I am looking like death*.

2.6.3 TB and HIV Disclosure

Janine Pierett (2003) argues the discredit depends on the 'discreditor', the circumstances, and the intensity of the discredit. She extends the definition of stigma into perceived and enacted experiences. Enacted stigma refers to instances of discrimination against people with a discredit on the grounds of their perceived unacceptability or inferiority. Felt stigma refers to the fear of enacted stigma but also encompasses feelings of shame associated with discredit.

When Bulelwa fully regained her weight she said she would ask those people who suspected she might have AIDS, *where is that AIDS you were talking about because I had TB*, although she never reported any enacted stigma towards her. Monakali and Xozza said they did not inform their girlfriends who lived elsewhere that they had TB.

Monakali said it was not necessary, Xozza said he could, even if he had HIV but did not tell her about his TB. Moya told his girlfriend, friends, colleagues and family that he had TB. He thought his girlfriend and some of his friends had stopped visiting him because they must have suspected that he has AIDS. He also disclosed his HIV positive status to his family and a friend. Virginia Bond and Laura Nyblade (2006) argue that in settings with high prevalence of HIV/AIDS, the disease has changed the experiences and perceptions of TB in many ways. Since TB is an opportunistic infection in people with HIV, there is confusion whether someone has normal TB or new TB. The authors affirm that a new disease stigma has emerged in community discourse, namely TB-HIV stigma.

Beshela, Bulelwa and Nobantu disclosed their status to some adult members in their families, but not to their children; and outside the family, they told a few close contacts who are also living with HIV, and they usually meet on their appointment days for treatment. Beshela said people in the shebeen often ridicule those with HIV; and Bulelwa feared people would label her as someone with 'LOTTO'. Gaba said that when she was young, she had a lean body and if she were still slim these days, people would think she has *le nto*- this thing. She said people should not ridicule those with HIV because, *le nto* is in everyone, it is going to appear at a later stage when people get sick and confined to bed. Nobantu keeps her status from her boyfriend and avoids Mbekweni clinic. She claims that the health workers are rude and not confidential, so instead she goes to a clinic in Cape Town to receive her anti-retroviral medicine. This claim is similar to Bulelwa's account of her VCT where the counsellor tends to normalise HIV and breached confidentiality by saying Bulelwa should not worry, as she was not alone; everyone who came out of that counselling room is HIV positive.

Nofirst and Rainy went public about their status, possibly to maintain their social relations and challenge stigma against PLWH. Rainy said she found it easy to talk about her status to family and friends. After learning about her status, she disclosed to her estranged husband and encouraged him to go for a test. He dissociated himself from the possibility of infecting Rainy and said he would not go for HIV test. Rainy told people in the shebeen not to be scared and ostracise her because she is not infectious because she

treats her HIV. Rainy said she believes in teaching others about HIV and said people must not insult those with HIV because *...le nto is a chain*'. Rainy tried to persuade her niece to go on anti-retroviral medicine and said about her experience, *you just tell yourself you have 'it' and you will take tablets, you won't turn back again*. Unfortunately, her niece died in June 2008.

After being diagnosed with HIV, a woman from the neighbourhood saw Nofirst coming out of the counselling centre and out of curiosity she asked why Nofirst came out of that room. Nofirst told the woman that she went for VCT and the results were positive. The woman did not believe her and kept on passing by her house wanting to confirm if Nofirst was telling the truth. Nofirst then told a tenant who has lived there for many years. She then phoned her uncle and a cousin in the Eastern Cape. However, after knowing her status, it was hard to tell her children until a friend came by and broke the news to Nofirst's elder daughter. Nofirst's public disclosure happened first at a funeral in her community although she said she was still scared to open up, and later by disclosing on World AIDS Day.

These findings about acceptance and disclosure confirm earlier research by Norman et al (2005) that disclosure among PLWH in Mbekweni was a stressful process not an event. Norman et al (2005) concludes the study participants' decisions to disclosure relates to Paxton's account that, 'the irony of disclosing one's status publicly by challenging AIDS-stigma', is that on the one hand disclosure carries a psychological freedom from the burden of secrecy and shame. On the other hand it may be a dangerous thing to do since one faces the possibility of rejection and discrimination, it can eventually be the most liberating experience (Norman et al, 2005).

In his study among fourteen respondents who comprised of professionals, counsellors, educators, and local NGO workers, (Norman, 2005) found that before participants disclosed their status to their families and partners, they anticipated rejection and abandonment, but also felt burdened by the guilt of not disclosing. When they did disclose they described the feelings of being, 'free, 'lighter', 'unburdened'. Although

some people felt rejected, abandoned and stigmatised by their partners, they found material and emotional support from their neighbours, relatives and friends.

In VCT, people living with HIV are encouraged to accept their condition and identify a confidante soon, to be able to cope with the disease. While the clinical discourse of acceptance and telling is believed to be 'therapeutic and empowering' (Leonard and Ellen, 2007), Disclosure for the five people who were co infected with TB and HIV, and the two who had TB was difficult as TB is linked to HIV/AIDS and HIV/AIDS is a stigmatised disease. The informants engaged in a psychological scrutiny of what people in the community would say about them. Nevertheless, they opened up to kin, close friends and a few people who are also living with HIV. Xoza and Monakali decided to make 'telling' not so serious, while Bulelwa and Beshela saw 'telling' as a problem. On the other hand Nofirst and Rainy were aware that 'telling' was problematic but after struggling with full disclosure, they protected themselves from stigma by opting for an advocacy role in their community and were coping better with their status, perhaps felt empowered through participation in the support groups for PLWH.

CHAPTER THREE

SUPPORT NETWORKS

3.1 Introduction

The findings show that families were not coping with illness without external welfare support. Social capital was found to be chequered in Mbekweni at organisational and community level. Close family provided social support to the sick, and substantial financial support came from the state in the form of welfare grants. Only in Bulelwa, Monakali, Speech and Xozza's families the heads of households were in regular employment during illness period. Speech and Xozza's family managed to secure enough food due to having regular income. Seven families supplemented their grants with seasonal farm work and were food insecure. In this chapter, I discuss the strategies the families used to cope with TB and HIV illness and food insecurity, from diagnosis, therapeutic searches, and cure and beyond cure. The core of this chapter, within the three bodies framework argues that the body politic is a synthesis of the body self and the body social.

Scheper-Hughes and Lock (1987) define the body politic as,

Regulation, surveillance and control of bodies in reproduction and sexuality, in work and leisure, in sickness and other forms of deviance and human difference'

The authors argue that body politic is an important and dynamic phenomenon as such analysis suggests the reasons and the manner in which particular kinds of bodies are socially constructed. The question whether the external support that the families relied on was sufficient or sustainable provides a multi-level analysis of the link between the macro and the micro socio-economic factors that make people susceptible to disease. As Vumisa, an elderly man from Phola Park Garden group retorted, *once a person gets poor there is always a disease*. I now turn to a discussion about social grants as a major source of income for many families.

3.2 Imini Yoncumo

(Translation: A day of smiles: the grant payout day)

On the day I had planned to visit Rainy's family for the third time, I first went into Max supermarket and noticed that 'hampers' were already on display at the entrance, for grant recipients. The store van normally delivers purchases within two days. Those who would have some left over from a previous purchase can wait for the delivery, but for those whose grocery cupboards are already empty, they come with their children to carry their hampers. I went down towards the community hall where marketers laid down their wares on the ground or on small tables that they brought, covered under big umbrellas or small tents. Wares range from cooked and uncooked food, new and second hand clothing items, blankets, curtains, cosmetics, fruit and vegetables, sheep heads and 'pens'-offal, chicken feet, live, and slaughtered and plucked 'umleqwa' (the term comes from chasing a live chicken for slaughtering which costs more for the labour involved).

Marketers come from different areas around Cape Town. Moya indicated that he bought his herbal medicine from a woman from Cape Town, and Rainy took a blanket on credit from a woman from Cape Town. For security, guards were standing with their riffles at the community door and only people with legitimate identity grant cards could enter the hall. While some people were standing in the queue to get into the hall, others moved around the stalls for their pickings or "just surfing". Some were standing around the "braai" area to indulge in barbecue. An elderly woman who participated in a group discussion said in most cases men eat at the meat stalls and the women always think about their children and take the meat home. I reached Rainy's home that was two streets away from the community hall. After speaking with Rainy, I went to her father's room and found Sam preparing to go to the community hall. He said with a sunbeam smile '*namhlanje yimini yoncumo*' - today is a day of smiles- a grant payout day.

Sam's sunbeam smile would fade away in a few days as his grant would be stretched over family expenses that normally exceed the amount received, and the family left struggling and at times forced to borrow money that in most instances is paid back with interest.

‘Imini yoncumo’: implicit in this metaphor is a conflict between this day being lovely as it brings brief relief from hardship and tensions that may ensue following the use of this resource by recipients. Families managed to secure a ‘hamper’. A hamper costs between R169 and R200, participants in the focus group discussion believed those who spent up to R500 to be fortunate as they managed additional foods such as meat, sausages, eggs, cereals, etc. As the woman from the peace committee group said, *the grant gets finished the same day; it is the same as nothing*. However, the grant brought some relief to families as this woman explained,

‘People spend the grant on medical care and food because the sick person cannot get better if there is nothing to fill the stomach, do you understand, buying clothes is not a priority although people need warm clothes to protect themselves from the cold. To manage enough food until the next grant payment depended on the size of the family, an employed member’s contribution, and a few debts to settle.

3.2.1 Negotiating Illness

Myer et al (2004) argue that studies that use income and expenditure, as a proxy for inequalities among individuals and households are misleading, and do not take account of assistance from extensive family and community-based networks. However, this study found income and expenditure to be significant indicators of better or worse family circumstances. The study confirms the findings of a recent epidemiological study that explored the relationship between HIV/AIDS sero-prevalence and skill level among Black and White South Africans, independent of ethnicity. Result showed that Blacks who occupied the same employment positions as their White counterparts showed higher prevalence of HIV/AIDS. Income inequality was a prominent factor in this study. Fassin (2003) affirms the findings validate that diseases among Blacks do not involve only a pathological process that paralyses the body but show the historical socio-economic inequalities and inadequate material conditions under which most Blacks live. People with TB and HIV were eligible for the grant, although accessing grants was a long and complex process. The waiting period for grant payout varied from two, four, and six months of treatment. Stanza finished his TB treatment in May but received the grant in

June. His partner, Lulu said they manage to buy the foods they desired since Stanza received the grant. Some grants stopped for PLWH as their CD4 count improved, others continued to receive the grant. For instance, Nobantu's (caregiver to Monakali) and Rainy's grant stopped and Rainy subsequently received it for TB illness, while Nofirst has been receiving the grant for five years.

Speech said he applied for the grant because he did not think he would be able to work again, and that he would have to rely on the grant. He said he was scared of *losing blood again because of hard work*. Misiwe assisted Speech by accompanying him to welfare offices to obtain the grant. She complained that she wasted time by going back and forth to the welfare office but she said she would be patient until the grant came out because as a sick person Speech was supposed to be getting some money. A day before Speech died in hospital he was at the welfare offices, and died within six days. Moya expressed the same feelings when asked how TB illness affected his life. He said,

I do not think I will be able to work again because I have a problem with my leg I will never be able to work again. I would ask the social workers and the doctors to help me.

Fiyo said the doctor referred him to Paarl East hospital for psychiatric observation, as the doctor must have noticed something wrong with his brains although he did not feel so. He said,

It was okay if that was the way I should benefit from the welfare, it was okay, many people have benefited from the government, who can refuse such a fortune?

Mpondo, a 50-year-old woman who did not have TB lived alone, had no income and had applied for the grant repeatedly because of her high blood pressure and arthritis; she was rejected several times. When she eventually received the grant, she brewed 'umqombothi' to thank her ancestors in a Xhosa way, for the grant. Her late daughter also lived with TB and received the disability grant. She said people in the community, because they knew she was struggling, gossiped about her daughter and asked what Mpondo would do when her daughter died and she no longer had the grant, as *if my daughter was enjoying her illness, she said*.

On the contrary, Nofirst said she did not want to depend on the grant, if she could get a job she would not mind if the grant stopped. However, she mentioned that when she goes for her ARV medication and assessment she avoids seeing a particular doctor because other people said he took people off the grant when the CD4 count was high and told people to look for jobs. Fortunately, early in 2008 she found a job with a local funeral undertaker. When Moya returned to work, his mother was concerned that his body was still unfit for work and he hoped that his employer gives him light jobs such as sweeping the floor and collecting tools.

‘The sick refuse TB, AIDS drugs to get state grants’ (HIV-AIDS, 2006). The story appeared in a newspaper that described how an unemployed father of two from Durban admitted that he deliberately did not take his TB medication so he could continue receiving the grant. He is quoted as saying, *how am I supposed to survive once the grant gets cut off, I will not be able to feed myself and as the medication makes one feel so hungry, and you need to have healthy foods to keep yourself well*. Some medical officers, who often recommend for the sick to receive disability grants, perceive TB and HIV illness as a ‘ticket’ to disability grants (Nattrass, 2006). Similarly, some Mbekweni residents believed that the people who do not complete their treatment want to stay on the disability, and blamed them for spreading TB in the community (Zamstar- unpublished data, 2005-2006). However, this was not the case in this study, as all the informants completed their treatment, even the two men, Moya and Speech who felt they deserved to stay on the grant because they have experienced the physical pain of TB and HIV illness and the hardship of coping with illness.

It is important to note that people might be compelled to default on their treatment to stay on the grant when they do not have buffers against hunger. Hence, Nattrass (2006) argues that the way the disability grant currently operates, will result in economic hardships for families whose income was only the grant and will affect the food security and well-being of people with TB and HIV. Therefore, the grant may create a perverse incentive to become and remain ill and disabled.

3.2.2 External support

People had more access to borrowing money and often resettling debt with the grant.

Aid from local NGOs was problematic as families received help occasionally. I found that there were more than 15 non-governmental organisations operating in the area but some participants in the group discussions had limited knowledge of their existence and contribution to the community. However, I attended a meeting organized by the health facility manager where various non-governmental organisations were invited and requested to take initiative in the set up of a soup kitchen at the clinic. Representatives from nine non-governmental organisations that deal with health related problems attended the meeting.

Many participants were against the local managers of food aid programs, accused the managers of favouritism, giving food to non-deserving recipients and keep some for personal use. In the minds of some community members, some organisations provide food aid only for people with HIV, a perception that might further stigmatise people with HIV. For instance in their evaluation of community involvement in the fight against TB and the weak performance of the DOTS programme in Cape Town, Kironde and Nasolo (2002) found that some of the barriers mentioned by the NGOs dealing with TB, were: lack of funding, lack of adequate collaboration, competition for funding, and paucity of human resources.

A participant lamented, 'people are keen to give money to AIDS, when in fact, you don't even have to ask, it's just out there. But for TB, unless you can convince them that there is a link with AIDS, people are not keen, so even for the companies wanting to get some social responsibility mileage, somehow giving to AIDS gives more mileage than TB' (Kironde & Nasolo, 2002). The assistance to PLWH depended on their readiness to disclose and join a support group or in other families on the degree of hardship and disability. Even within the support group, there were sub divisions. No first mentioned that those who were on anti-retroviral treatment would first meet at the clinic on Wednesdays to share experiences and information about anti-retroviral medicine.

They later joined a bigger group at Catholic Welfare Development. There was no support group for people with TB.

Janine Pierett (2003) affirms that some people cope with illness by isolating themselves from the public or by participating in self-help groups. Self-help groups are mechanisms for establishing organisations in which people with disabilities have a voice and a power to challenge the media and public authorities in the fight against stigmatisation. The literature on HIV states that disclosure enables people to cope better with the disease, access medical care and social support (Norman, et al, 2005). Bulelwa did not know what a support group was although she was struggling with her status. Beshela was less interested in the support group and said she was not talkative. While Gaba used her social networks and borrowed money to buy fruits for Beshela, Bulelwa and her mother, Nozibele were reluctant to borrow money and anticipated stigma as she said people would gossip about her family because they had noticed Bulelwa had lost weight and they had seen her at the clinic. People would say her family was struggling because Bulelwa has AIDS.

The community identified people with HIV at the clinic and at the support group centre. Nofirst also mentioned that since the support group centre is next to a shebeen, some people from the shebeen come out to see who attended the support group.

In a study of the experiences and expressions of stigma among PLWH and Home Based Carers in KTC, Gugulethu, Mills (2006) found that a mother of an 18 year-old woman who was HIV positive, refused visits and food parcels from the home based carers though she was unemployed and the family was struggling. She feared that the neighbours would stigmatise her and the whole family, and they would undermine her mother's social status (Mills, 2006).

Moya was also encouraged by another friend to come with him to the support group. He attended a few times but he was not happy because of group in fighting. Moya was reluctant to go back to the group and his mother insisted that he attended so that he could

get food aid and clothing. Moya received a foam mattress from Caring Network as he was sleeping on the floor in the main house. He was also given food parcels twice which comprised of a 2,5 kg bag of samp, maize meal, flour, sugar, cabbage, soya mince soup, Ellis brown coffee creamer, 1kg dry beans, 1tin of pilchard, 500ml cooking oil, yeast, tea bags, sunlight soap and a packet of 12 beef stock cubes.

Rainy's family benefited occasionally from NGOs. Home based care workers from the Caring Network often visited her father. Her niece Loza, before moving out, received a bag of potatoes, onion, rice and a packet of mixed vegetables by CWD. Rainy's son received 5kg flour, rice, sugar and cooking oil from ADP, a project of World Vision. Nofirst received food parcels every month for her participation in the support group of PLWH that runs at the Catholic Welfare Development in Mbekweni. The parcel consisted of soya soup, 1 kilograms mielies and maize meal and 500 grams of sugar, sometimes potatoes, 12 kg of sugar and maize meal. Employers also provided support: when Speech died, his employer contributed towards funeral costs and advised the family about his employment benefits. Nobantu also negotiated advance payment with her employer to extend and renovate her house; she also anticipated financial assistance for her divorce proceedings.

3.2.3 Caring as reciprocity

The moral character of kinship among Xhosas originates from the cultural normative order that families need to support one another in the short term for long-term relations. These ethnographies reveal that kin networks can be both a buffer against poverty or a cause of poverty through the creation of forms of inequality around gender, generation, or other positions, when inter or intra-household exchanges occur in the form of labour, space, money or emotional support (Booth et al, 1999, de Waal & Tumushabe, 2003, Goudge & Govender, 2000). TB illness resulted in lost earnings as eight of the people infected with TB stopped working. In the early stages of illness, they were dependent on their families for emotional, practical and financial support before they received their disability grant. Two of the ten, Fiyo and Nofirst, were already on disability grants, and

received practical and emotional support from their kin. Care within the family fell on female kin, as indicated in the table in Chapter 2. Friends and boyfriends provided practical, emotional and financial support. Nobantu often borrowed money from her friend. Noloyiso received a disability grant for living with HIV. On one occasion, the grant payout fell on the day Nobantu wanted to be at work. She then asked Noloyiso to come with her to work to give a hand so that Nobantu could finish early, and receive her grant. Rainy and Beshela reported that their boyfriends often gave them money. Although Beshela claimed that, her boyfriend supported her financially, when she told him that she has HIV and advised him to go for a test; he refused and accused Beshela of infidelity. As a result, they were no longer together. Nofirst received emotional support from her boyfriend. Nevertheless, Rainy and Nofirst's relationships were not always easy since they claimed that their boyfriends did not want to use condoms and the women were concerned about their CD4 counts dropping. Fiyo and Stanza received emotional and practical support from their girlfriends, and Fiyo's niece cared for him.

The complex and fluid nature of kinship composition and networks challenges the generalised definition of a household often used in surveys, as a bounded entity in which family members live under the same roof, share food and combine their resources.

As Goudge & Govender (2000) argue the conventional definition of a household as coherent and discrete tends to falsify the processes of a domestic life shaped by kin networks. Erik Bahre (2007) concedes that although some kinship studies have reported on the functionality and stability of kin networks, they have not fully examined the rivalry and conflict amongst the kin, which these narratives have shown. Sandra Wallman (2005) suggest that more attention ought to be paid on the developmental cycle of a household, as it grows, blends and splits, rather than on its social form. Thus, it is critical to understand how the socio-economic resources at the disposal of different households can influence the fluidity of households.

The normative expectation of roles and reciprocity amongst kin also played out when people with TB started to receive their disability grants. When the expectations did not

materialise, tensions and new conflicts ensued within families. When Gaba and Thethiswa were talking about the special foods that they had to buy for Beshela while she was ill, Gaba said Beshela had wasted their money and she hoped that when Beshela got her grant she would save money and not spend it on liquor. When Beshela received her grant, she paid R300 for her sisters' trip to Eastern Cape and bought her some food because they looked after her when she was ill. As Beshela gradually returned to health, she began to do chores. During my third visit I found her doing laundry for the children and said she had just finished washing her sister's clothes. When I asked why she was doing laundry for her sister, she exclaimed,

'Yho' they talk too much, they would say, we took care of you while you were sick now you are healed and do not want to help us.

Beshela and her father had a shaky relationship. Her father did not contribute to family expenses and spent his money on liquor. I visited the family on the day he received his grant and Beshela said if it were their mother's payday they would be eating meat and had cool drinks and would not be sitting like orphans with no father to provide for their needs. She manipulated her father by demanding money to pay for her burial plan, swearing at him and saying *my lobola went down your dirty throat*. She said he felt guilty and gave her R100, and she resolved to swear at him every time she wanted money for her burial plan. Beshela spoke of mixed feelings between her and her father:

The person who does not really care about me is the man of this house, he could beat me up right now, and when he is drunk, he becomes a nuisance. When he is drunk he says, go away, you willingly went back to your in-laws, they stole your money now you are miserable here, we are not the ones who stole your money. My father is so affectionate to me when he is not drunk he would say they must not make you work hard because you are sick.

Nobantu lived beyond her means and spent less on food because of repayments of debts, thus she expected Monakali to help her with food. But Monakali spent his grant on entertaining his friends and bought liquor. Tension between Nobantu and her older sister erupted over Monakali's use of the grant; Nobantu accused her sister of being a bad

influence on Monakali by drinking with him. Towards the end of treatment Nobantu said she was going to organise someone to fix Monakali's shack for him because she worries about her brother's health and that he might die; of major concern is that he does not have insurance cover for death and she cannot afford funeral costs. At a celebration for her daughter's birthday, her brother and her youngest sister got into a fight after drinking. The youngest sister ridiculed Monakali about boils on his face and saying she wished he could *"be stabbed and die"*, that prompted Nobantu to intervene, saying, *"Our brother is our blood, there is no garbage bin to throw him in, he needs our support"*.

A similar experience occurred with Nofirst's brother Tokwe. Nofirst complained that he spent his money on liquor and had not paid his burial plan, and had not bought enough food: *yes that's the only groceries he bought when he got paid his grant, he bought sausage and two packs of chicken portions. That is all, nothing to eat the meat with*, she said. She called on social workers who had helped them obtain the grant to speak to Tokwe about his behavior. Her brother protested that Nofirst was his mother: *you are not my mother to reprimand me, you must not bother yourself – if I must die, let it be*.

By the end of the study, the brother had started work and the relationship between the siblings had improved. Fiyo's sister worried about his misuse of grant, taking things on credit and being a victim of hawkers who overcharged him because he could not remember the amount he owed them. Fiyo retorted that his sister wanted to control him. Rainy also complained about her sister who came from the Eastern Cape, that she was not buying food, but Rainy was not sure if her sister was still receiving her disability grant. Xozza's father did not understand the physical impact of TB illness, when in the early stages complained that Xozza was lazy and his behaviour would influence other children not to do chores. Moya's mother said it is difficult for her to monitor Moya since he resumed work and moved back to his shack. He did not share food with the family. She was not sure how he was eating as sometimes he was out with friends or drinking at Vusa's shack. Mamthi said, *he is not taking his health seriously, I have spent a lot of money caring for him, hiring cars to hospital but I am not complaining because I wanted him to heal. If he gets sick again I am not taking any action*.

Erik Bahre (2007) argues that the classic ethnographies by Laughlin (1974) revealed how deprivation and increased food insecurity led to the contraction of solidarity networks, as reciprocity was more balanced and less generalised among the So in East Africa. Turnbull's (1972) study among the Ik group also in East Africa describes the disintegration of a society to an extent that there was reluctance to offer basic care and support when people needed it. Bahre argues that these ethnographies have been highly criticised for portraying the poor as uncaring, immoral and for undermining capabilities of the poor to build solid social relations to deal with adverse social conditions. However, some contemporary, urban studies like this ethnographic study reveal similar dynamics of social relations and poverty, which some literature have refuted. In his study of solidarity and social networks among Xhosa residents in an impoverished community in Khayelitsha, he found that loss of income and increased vulnerability affected neighbourhood relations, trust and solidarity, to an extent that it may be impossible to support even the most intimate family members (Bahre, 2007).

TB and HIV illness, and other adversities did strain kin relationships among my informants but kin were vital to managing and surviving TB, through provision of necessary food, personal care, and making sure that the sick had access to their medication.

Table 2: Socio-economic Status of families affected with TB and HIV

	TB Patient Profile	HH members	HH Composition	SES	Wealth Ranking, Section & Food Security
HH 1A	46-year-old woman Head of Household (Hoh)	5	Hoh 46 yrs (TB patient) Brother 57 yrs (recently had TB) Daughter 27 yrs Daughter 10 yrs Grandson 7 yrs	* Received land restitution * No employment. Earns money from shack rental, craft –work for PLWH * Patient received disability grant for HIV + status since 2002 * Brother received disability grant for TB, piece meal jobs * Lives in own row house	Better Off Well off area Food Secure
HH 2A	31-year-old woman	5	Hoh 51 yrs (woman) Daughter 31 yrs (TB patient) Daughter Granddaughter 12 yrs Granddaughter 9 yrs (Daughters of the patient)	* Hoh works full time at a fast food restaurant * Patient receives child support for 2 children, stopped work after TB & received a disability grant * Live in rented shack	Poor Mixed area: poor & well off Food Insecure
HH 3A	24-year-old man	4	Hoh 33 yrs (woman) separated from husband Brother 23 yrs (TB patient) Daughter 13 yrs Daughter 4 yrs	* Hoh full time domestic worker and receives child support for 2 children * Earns money from shack rental * Patient received disability grant (stopped farm work after TB) * Live in own RDP house	Poor Poor area Food insecure

HH 4A	36-year-old man	3	Hoh 40 yrs (woman) Partner 36 yrs (TB patient) Girlfriend's son 18 yrs	<ul style="list-style-type: none"> * Patient self employed repairing cars, TVs & radios and receives disability grant * Partner farm seasonal work * Live in partner's RDP house 	Poor Poor area Food insecure
HH 5A	Hoh 61-year-old man	2	61 yrs (TB patient) Partner 55 years (woman)	<ul style="list-style-type: none"> * Lives in shack * No employment * Patient receives disability grant * Patients sells & grows traditional herbs * Partner collects rubbish 	Poor Poor area Food secure
HH 6A	50-year-old man	11	Hoh 74 yrs (woman) Son 50 yrs (TB patient) Daughter 39 yrs Daughter 35 yrs Son 37 yrs Daughter 31 yrs Granddaughter 20 yrs Grandson 14 yrs Grandson 16 yrs Grandson 5 yrs Grandson 2 months	<ul style="list-style-type: none"> * Received land restitution in 2005 * Hoh received old age grant 2 daughters do farm seasonal work * Son receives disability grant (psychiatric problems) * 2 children receive child support * Earns money from shack rental * Patient did seasonal farm work but stopped after TB * Live in own row house 	Poor Mixed area: poor & well off Food insecure

HH 7A	39-year-old woman	8	<p>Hoh 83 yrs widower (died during fieldwork)</p> <p>Daughter 39 yrs (TB patient)</p> <p>Granddaughter 29 yrs</p> <p>Grandson 18 yrs</p> <p>Grandson 14 yrs</p> <p>Granddaughter 8 yrs</p> <p>Grandson 4 yrs</p> <p>Granddaughter 12 yrs</p>	<ul style="list-style-type: none"> * Received land restitution * No employment * Hoh received old age grant * 3 children receive child support grant * Partner to patient gives financial support * Earn money from shack rental * Lives in own row house 	<p>Poor</p> <p>Mixed area: poor & well off</p> <p>Food insecure</p>
HH 8A	50-year-old man	7	<p>Hoh 56 yrs (man)</p> <p>Wife 43 yrs</p> <p>Brother 50 yrs (TB patient)</p> <p>Daughter 22 yrs</p> <p>Son 19 yrs</p> <p>Daughter 13 yrs</p> <p>Son 13 yrs</p>	<ul style="list-style-type: none"> * Hoh in full time employment (for Municipality) * Wife does seasonal farm work * Daughter work in a pharmacy * Patient works in construction before TB, died in process of applying for disability grant * House in Eastern Cape * Family dwelling, in process of building own house 	<p>Better off</p> <p>Mixed area: poor & well off</p> <p>Food secure</p>

HH 9A	30-year-old man	7	Hoh 58 yrs (man) Son 30 yrs (TB patient) Son 22 yrs Daughter 25 yrs Nephew 40 yrs Daughter 10 yrs Granddaughter 6 yrs	* Hoh in full time employment in construction * Patient employed (general worker) & receives disability grant * House in Eastern Cape * Live in former hostels: will get own family unit	Better off Housing becoming better off Food secure
HH 10	32-year-old woman	8	Hoh 66 yrs (man) Wife 71 yrs Daughter 32 yrs Daughter 36 yrs Granddaughter 11 yrs Granddaughter 10 yrs Grandson 15 yrs Grandson 9 yrs Grandson 7 yrs	* No full time employment * Hoh and wife receive old age grants * 4 children receive child support * Wife and daughter do seasonal work * Patient used to do seasonal work & received disability grant * House in Eastern Cape * Live in own RDP house	Poor Poor area Food insecure

3.2.4 Maintenance of health: agency and control

Janine Pierett (2003) states that illness experience is also fashioned by health policies, systems of care, state of medical knowledge, patients' associations and the media. Throughout the thesis, data shows that as people with TB and HIV search for the meaning of their sickness, illness narratives often reflect on encounters with medical professionals, non-governmental organisations, special care centres, folk healers, and the community. Scheper-Hughes and Lock's conceptualisation of disease and the body politic conveys a system of power and domination. Drawing on a Foucauldian view of the body, which regards it as subject to a specific kind of 'medical gaze', the authors argue that the medicalisation of disease has resulted in docile bodies that succumb to manipulation through invention of technology and drugs. On the other hand, critics of the medical gaze argue this view posits the body as docile and undermines its agency. Sharma (1996) and Crossley (1998) affirm that patients do not only play a sick role but also become informants to their doctors (cited by Janine Pierett, 2003).

The discussion here considers both views, the docile and active bodies. It is along the lines of clinical encounters with diseased bodies that Butchard emphasizes that, according to Foucault, bio-power manifests through a disciplinary approach of examining bodies, diagnosing and prescribing the trajectory of disease. For instance, people with TB have are subject to rigorous management, watched over and controlled from diagnosis to treatment completion and cure. Encounters with doctors were marked with demands for testing and injection; misunderstandings of medical procedure as Beshela questioned the doctor who gave her injection on her arm. Rainy rejected misdiagnosis of gastro-enteritis and Nobantu could not understand when the doctors initially told her she did not have TB. Fiyo, Rainy, Beshela, Moya stayed in hospital for about two to four weeks during their illness periods. Although Beshela refused at first to go to Luthando Care Centre, when her condition worsened, she had to heed doctors' orders. When Stanza defaulted on his TB medication, the nursing sisters visited him at home, and DOTS supporters monitored Fiyo's intake of treatment.

Placing people under surveillance has long-term goals for their lives to prevent drug resistance and prevention of disease transmission to the population.

The lives of people with HIV depend on regular examination, advances in medical knowledge and strict treatment regimens. The medical personnel instructed PLWH to visit the anti-retroviral clinic at Paarl East every month to make sure that they live longer. They may not use other medications whenever they were not feeling well, and instead go back to the anti-retroviral clinic. It became a financial burden for some, as they had to find money for transport. As Rainy explained, *what happens is that when I do not have money I walk but that killed me because I come back tired*, she once asked the doctors for a fare to return home. While Mbekweni and Phola Park clinic started to provide ARVs in August 2007, this program has not brought relief of transport costs to Rainy and others in similar circumstances, as only new people on ARVs will get them from these clinics. Beshela forgot to take her medication for two days, when she went back to the clinic the doctor reprimanded her, as Rainy insisted that, *there is no turning back you have to take your medication*.

Similarly TB has always posed a challenge to public health practice from testing only people who present with TB related symptoms to the health centres, to using different methods of testing which may detect or fail to detect the mycobacterium bacilli, to low cure rates. South Africa has embarked on stringent measures to control drug resistance strains by putting people infected with Extremely Drug Resistant TB, the Stop TB article reported, *'Behind high fences patrolled by guards to prevent escape...critics say enforced quarantine is a violation of medical ethics and individual human rights. Health authorities-who earlier in 2007 resorted to the courts to compel four patients to stay at the hospital-say they have no choice'* (Stop-TB News, 2007).

The article further states that a taxi driver with extreme drug resistance TB refused to be admitted as he was worried about the loss of earnings, but eventually accepted after he was made aware that he was endangering the lives of many people. The example of this taxi driver is similar to Moya's as he forced himself back to work although unwell, to

work under the same conditions he claimed had caused his illness.

He also had to make a hard choice of losing earnings, or risk his life by not going for his ARVs for three months. During the group discussion about work opportunities, a woman said, *during seasonal work there are few people who fall sick, even the sick rush to the farms and pay no attention to their health*. A nursing sister at JJ du Pree le Roux hospital in the Drakenstein region confirms that the problem of treating TB effectively in Paarl is the cycle of seasonal labour. Farm workers work long hours and find it difficult to go to clinics for their treatment (Paarl Municipality, 2000). Therefore, due to lack of safety networks the poor have to depend on their bodies for survival when there is a window of opportunity to earn money. While people benefited through the temporary strategies to alleviate their poverty, the long term-health risks are high.

Control and surveillance of people with infectious diseases is not a new phenomenon in South Africa. Butchard (1997) further argues that diseased bodies are the manifestation of the sovereign power invested in medicine in South Africa during the colonial period, which viewed African bodies as carriers of diseases and a threat to European bodies. Consequently, the endorsement of the public health policies of the slum clearance and 'native locations' in the 1800s, resulted in segregation of urban settings according to race and class. The first removal of Africans occurred in Cape Town in 1900 after the outbreak of the plague. As it happened in the mines, instead of improving the living conditions in the 'native locations', public health authorities had to educate Africans about good sanitation and control their movements. The apartheid system heightened these regulations, and segregation influenced by the ideology of race superiority permeated all aspects of African livelihoods.

The discussion above suggests that the control of diseases is not an individual responsibility; however, a complex situation arises between the interests of those who are powerless and those who have to manage and control diseases. In Butchart 's (1997) chronicle of medicine and the creation of the African patient in South Africa, he suggests, instead of viewing medicine as having sovereign power over docile bodies, it be

understood as a disciplinary power. Where sovereignty proves to be an influential source of repression and negation, discipline has become a productive force that those in power use to investigate and keep track of every contact with bodies that needs continual analysis and manipulation through technological advances (Butchart, 1997). This discussion highlights a host of structural factors, for instance, on the one hand the control mechanisms put in place to benefit and improve the health of individuals, communities and wider population. On the other hand, those who are at risk of TB deaths, and those who pose the threat of TB to others, feel prevented from earning a living, and feel repressed and ostracised from their kin and communities by admitting to go to sanatoriums, where they have to adhere to health regulation

CHAPTER FOUR

THE WIDER CONTEXT OF VULNERABILITY

4.1 Introduction

This study found that the livelihoods of the families without TB were not different from those affected with TB and/or HIV, as will be shown in the case studies in the first section of this chapter. Eight of the ten families experienced some lifestyle-related illnesses such as high blood pressure, asthma, arthritis, diabetes and stroke, and needed medical care. Although seven of them, except for Maxaba's grandson who has HIV, also needed food before taking medication, their condition was not as compelling as it was for people with TB and HIV, since they did not crave special foods because of their illness. However, sources of income and expenditure were similar across families. Four families, which I have denoted number 4, 6, 8 and 10, often struggled to obtain enough food. These findings supports the notion that it is crucial to understand the social context of vulnerability as Bates et al (2005) show in their studies of socio-economic status and TB incidence in the United States of America, that a poorer person had a 2, 3 % higher risk of infection than the wealthier person living in the same area. However, studies from Mexico and South Africa found no variation in socio-economic status of TB patients and non-TB patients living in the same community. The authors call for different methodological approaches to interrogate how the different forms of poverty shape illness experience (Bates, et al, 2004), which this study attempted to do.

4.2 Case studies of the ten families without TB

Case Study One

Nceke is 61-year-old female head of the house. She survived on old age grant and petty trading from home and at a local school. Her son Mbara is single, lives and cooks alone in his shack at the back of the main house. Nceke and Mbara have a shaky relationship and hardly speak to each other.

Nceke is suffering from arthritis and severe varicose veins. She sees a private doctor occasionally and for each visit pays of R140. She suspects that her son is HIV positive because she has seen him taking some medication, and Nceke's neighbours have told her that her son was attending an anti-retroviral clinic but he has never told Nceke about his illness. She blames the government for promoting confidentiality around HIV disclosure, which makes it difficult for parents to care for their children and that parents face a risk of transmission when caring for the sick, not knowing the diagnosis.

Case Study Two

Hilda is a young woman of 36 years. She has a full time job as a community health worker and earns about R800 a month for this work. She receives a child support grant, and her live-in boyfriend was a general worker at the municipality offices. They are renting a shack and the family was food secure but at times she borrows money from friends and relatives.

Case Study Three

Nodumo is an elderly woman; she received an old age grant, and supplemented it by selling beer and taking ground rental for three shacks. She also maintained her house in the Eastern Cape, and her two sons found casual jobs. She has land in the Eastern Cape, grows maize, and normally gets 10 bags of 50 kg each. She says in the last harvest she sold four bags, consumed three and she gave away the other three bags. She spent her grant on travelling every two months between the rural and the urban home, until she received her grant through the bank. I met her three times before she settled in Eastern Cape until the end of fieldwork.

Case Study Four

Mpondo lived on handouts, intermittent remittances from her son when he has a piece job. She received food aid from Caring Network consisting of rice, mealie meal, flour, samp, sugar, tea bags, stock cubes, fish, yeast, jam, beans, and sunlight soap. She stopped receiving food aid when her disability grant came through. She occasionally sees a doctor for her illness and pays R150.

Her son who is living in Daal stayed in hospital for 2 weeks at the beginning of June 2007. They hired a car for R100 to take him to hospital; the visitation to hospital itself cost R40, which she paid from the grant. After leaving the hospital, he stayed with her mother for 6 days and then moved back to his shack. Her son also had TB. Anxious about his son's health and following the death of her daughter a few years before from TB, Mpondo mourns: *Where does this TB these children have come from'? No, these children of mine are going to die now while they are old, I see they never got sick when they were young, is it still TB alone, what kind of TB is at the back?'*

Case Study Five

There were six people living in Maxaba's home. She is the head and receives two disability grants for herself and Dodo's HIV positive status, and a child support grant for the child she was fostering. She is on treatment for arthritis and Dodo is on ARVs since 2002. Dodo's mother died of AIDS related illness in 2000. Dodo's father rejects his son because the community knows that Dodo's mother died of HIV/AIDS illness. Therefore, he does not want his image spoiled. Maxaba needs to buy special foods for Dodo, such as vegetables, cereals and milk, as a doctor at Paarl East hospital told her to buy these kinds of foods. Maxaba must fetch Dodo's medication every month from Paarl East hospital and she pays R20 for taxi fare. Her son is in prison and he phoned her to tell her that he got sick and admitted in hospital, that he had a blood test and the results showed that he is HIV positive. Her daughter Nomfazi worked as a prison warder. Maxaba also sells small things from the house, such as sweets, cigarettes, ice cubes, biscuits and chips. She gets between R20 and R50 a week, and shack rental of R50. She sometimes took food on credit from local hawkers.

Case Study Six

Mambe is a 50-year-old woman. She received a disability grant for her high blood pressure and possibly living with HIV. There were two child support grants. She also worked for a school-feeding scheme and earned R250 a month. Her daughter worked on farms and her son found casual jobs.

Mambe also received food aid from the Dutch Reformed Church where she is a member. She has to go to Paarl East hospital every month for her treatment besides the treatment she gets at a local clinic for high blood pressure. When I asked her about her treatment she gets from Paarl East Hospital she said she has her own illnesses about which she was not prepared to share with us. When Mambe does not have money she relies on the bread and other foods she brings back from the school. She expressed her hardship, '*Kunzima (it is hard), kuphandle- (literally means living in the space) there is nothing, it is sad to live off borrowing from other people.*' I visited her when there was not enough food in the house, she talked about a relative who eats nice breakfast such as eggs, bacon, and fresh bread and said, '*I last had that kind of food when my father was still alive.*'

Case Study Seven

Nyanga and Langa were on old age grants and coping well. There was also a shack rental of R50 a month. He mentioned later on that he is getting a pension payment of about R400 a month from his previous employer. Langa had stroke and now uses a walking stick. Nyanga drinks and he insist that he drinks only one beer when alone and does not drink to get drunk because, '*I am not like those young people.*'

Case Study Eight

The following example shows how some people abuse a social grant, and the vulnerability of the disabled. Babe is 53 years old, disabled and receives a grant. She lived with her sister's teenage children, Price and Zara. Her sister remarried and the children have an uncertain relationship with their stepfather. Nolwandle, Babes' niece lived in the main house and Babes contributed R200 a month for food as she sometimes had difficulty taking care of herself because of her disability.

Nolwandle receives the foster care grant for Price and his other two siblings who live in the house. Zara did not get food from inside the house because she and Nolwandle were not on good terms. Zara left the house after she quarrelled with Nolwandle, and she lived with relatives in Milnerton. Zara came back but Nolwandle did not accept her.

She shared a bed and food with Babes; sometimes she cooked in the shack. Babes claimed that the reason Nolwandle chased Zara out of the house was because Zara's foster care grant stopped. May be when Price's grant stopped Nolwandle would chase him out as well. Babe's family often neglected her needs; at times, she skipped her meals because there was no one to prepare food for her. She would then buy a piece of fried fish from a spaza shop or snacks until the next meal comes.

Case Study Nine

Xolelwa was a community health worker but stopped working when she fell pregnant. Her child was born with a respiratory infection, so she stayed at Red Cross Children's Hospital for three months. I did not see her until the end of the fieldwork period. Unfortunately the child died later in hospital. For subsequent visits I met with her sister Zwide. The family lived on two child support grants, and Zwide did seasonal farm work. They lived in a hostel before and moved into a new RDP house in Langabuya. Although the family said they were happy to have their private space, they used most of their grant to renovate the house and bought materials such as carpets, curtains, and electric stove as the municipality ordered the new tenants not to use paraffin stoves to avoid fires. They said there were inspectors doing rounds to ensure that people followed the law.

Case Study Ten

Madlamini is 58 years old and the head of the family. There were seven people living in the house. Madlamini is suffering from high blood pressure and she receives a disability grant of R890 a month and a rental of R50 from one lodger. Her daughter Nomathe is a counsellor at Life Line in Khayelitsha. Madlamini's son Zola was unemployed and looking for work. He later found casual jobs and his wife worked on farms during season. The elder son lives separately in a shack but contributes between R20 and R40 for electricity. There were often fights in this family, because of which Madlamini called on social workers and the police to intervene. She once considered leaving the house to stay in her rural home in Eastern Cape.

I visited Madlamini on the day she was not well. She complained about a headache and hunger. She was worried that I visited them when they had no food. Selina (Madlamini's daughter in law) took a slice of bread that was kept for her and made tea. They kept the bread for Selina because she was breast-feeding. Madlamini said Selina needed pap and cabbage because breastfeeding would make her weak if she has not eaten something sustaining. A relative walked in and asked for food; Madlamini said they were fasting and drinking water (meaning there was no food). She switched off the fridge and said it was wasting electricity because the fridge was 'yomile' (dry) empty. She said there was no paraffin to cook *umgqusho* (samp and beans) and cooking on the electric stove would consume much electricity. Madlamini was also worried that the children would come back from school hungry and found no food in the house. She said, *'This has never happened to us before; the sun goes down without eating anything! I get so worried and ashamed when I do not have food and get visitors like you; there is no dry yeast to make bread. Food is expensive; R500 for food is nothing it gets finished before you even buy meat. 'Kunzima' - it is hard, maybe I must ask my daughter to buy tinned food maybe its going to last.*

4.3 Mbekweni: a research site

'Mbekweni' is a Xhosa word that denotes 'a place of respect', however a female respondent who lives in a shack said the name is relevant only to the railway station named Mbekweni. She alluded to life and social conditions in the area that were at times unbearable for the local people. This chapter gives a background and discusses some of the problems that face the community.

The population of Mbekweni was estimated to number 32, 000 in 2008 (personal communication with Nursing Sister- in charge at Mbekweni clinic). The majority are Xhosa speaking and some Sotho and Afrikaans-speaking people. Many have originated from the Eastern Cape and still have strong links with the Eastern Cape, often returning for holidays, rituals, initiation ceremonies and burial of kin as many people believe that cultural activities and burial are meaningful when performed in one's ancestral land.

This social pattern of urban-rural mobility is rooted in the migrant labour system, which prohibited migrants from living with their families, resulting in many spouses and children left in the 'homelands'. The repeal of migration control from homelands to major cities, in the mid 1980s, and the democratic transition resulted in influx of people from the Eastern Cape to the Western Cape, to join kin or look for better employment opportunities. The rural-urban mobility resulted in contracted space in the old townships; therefore, informal settlements began to sprawl in the outskirts of Western Cape cities (Ndengwa et al, 2004).

The Western Cape provincial department of health decided to celebrate the World TB Day on the 24 March 2007 in the Drakenstein region in the community of Mbekweni. Drakenstein is one of the districts in the Western Cape with high TB prevalence. The spokesperson of the Department of Health agreed that TB in this region is increasing at an alarming rate. The average per quarter was 543/100 000 in 2004 and increased to 718/100 000 population in 2006 (Paarl Post, March 2007). The National HIV Antenatal survey for the year 2006 showed a prevalence of 15% for the Western Cape. The Paarl district has registered an increase from 8.9 in 2004 to 12.6 in 2006 (Western Cape Dept. of Health, 2006). In a report of the socio-economic profile of the Paarl district, between 1999 and 2000, Dr Terrence Carter of Paarl East Hospital confirmed that most people who were diagnosed with HIV/AIDS came from Mbekweni, Fairyland and Paarl East (Paarl Municipality, 2000). Mr Mgajo, the speaker for the Drakenstein Municipal said TB and HIV spread in Mbekweni were due to poor living conditions. He highlighted that the Drommedaris area was a health hazard and said building proper houses will reduce effects of ill health in Mbekweni (personal communication, 2006).



Figure 2: Environmental issues

The area in picture 1 & 2 are in Drommedaris informal settlement along the railway station, picture 3- the place is between Phola Park and Langabuya. The above pictures are adapted from a report of Local environmental programs planned for 2002-2004 and initiated by the Drakenstein Local Council, a municipal body that Mbekweni falls under, and clearing up had not started until the end of fieldwork in 2007.

The same report mentioned that due to a shortage in housing, there are environmental, health and safety problems related to the conditions that people have to live under, and that TB and HIV in Mbekweni are of serious concern. However, the main concern of the environmentalist was the contamination of the Berg River. The report blames the Mbekweni residents for being non-cooperative, not using the waste containers provided by the municipality and lack of education in environmental matters.

http://www.iclei.org/documents/Africa/greener_governance_in_southern_SADC.pdf).

This case reveals the hierarchy of interests between those in power and the marginalised communities. Blaming residents for not taking care of their environment implies that the poor are responsible for their ill health, and the conditions in which they live. While the report pardons the municipality for providing the waste containers, it does not question the availability and quality of services provided to informal settlements by the municipality.

In essence, the authorities expect residents of these areas to adapt to the conditions that those in power have created, and locals are to respect the interests of the elite. This case reveals what Turshen (in Inhorn & Brown, 1990: 97) claims to be a tendency of ecological studies to ignore the 'political ecology of disease', as if Blacks chose to live in inadequate conditions, 'out of perversity rather than economic necessity' (Packard, 1989). As Merrill Singer (2003) emphasized that, it is imperative to understand diseases in the context of 'syndemics'. Syndemics do not only apply to the synergistic impact of TB and HIV/AIDS at the physiological and population level and social context.

'Syndemics occur when health-related problems cluster by person, place, or time. The problems- along with their reasons for their clustering-define a syndemic and differentiate one from another (though they may have overlapping relationships). To prevent a syndemic, one must not only prevent or control each disease but also the forces that tie those diseases together' (Singer, 2003).

4.4 Limited social networks

This section highlights the historical context of socio-economic status of the people of Mbekweni, and shows the mechanisms that link the body self, the body and the body politic. Many respondents reported that limited work opportunities for Africans were due to employers' preference for Coloureds. Participants strongly emphasised that the opening of new businesses in the Paarl district does not guarantee job prospects for the Mbekweni residents. Tshoboyi, an elderly man affirms that, *another thing that is happening here is people who are in positions at the Municipality offices, reserve jobs for their own families and friends and discriminate against the people who come from the Eastern Cape. Therefore, for that reason many people in Mbekweni are unable to find jobs and that is the biggest problem we have here.* This system of Coloured preference has historical origins and was used a mechanism to keep the majority of Africans away from cities. The most stringent apartheid legislations to separate the South African population along racial lines were the Group Areas Act and The Population Registration of 1950s. The latter required all persons over 16 years of age to carry a pass that identified the person's race.

The Bantu Authorities Act of 1951 strengthened the idea of 'Black reserves' which were created during the colonial era by European settlers, and planned separate governments for Blacks in the Bantustans. The Mine and Work Act of 1961 formalised racial discrimination in employment. Through these Acts, authorities declared the Western Cape Province 'Coloured labour preference area' (Berger, 1990).

The expansion of the industrial sector in the late nineteenth century resulted in the development of fruit canning factories in the Western Cape. The first jam factory opened in Stellenbosch and Paarl in 1925. The two dominant companies were the Laangerberg Kooperasie Beperk in Paarl and the South African Dried Fruit Company in Wellington in which in 1948 the largest number of the labour force was Coloured women, followed by African men, Coloured men and African women were in equal numbers. In the 1950s, the canning industry imposed sanctions on non-racial labour movement; as a result, there were two unions, the Food and Canning Workers' Union that was composed of Whites, Coloureds and Indians, and the African Food and Canning Workers' Union. Those in power in the agricultural and industrial labour formed an action committee to encourage employers to mechanise and replace unskilled African labourers with skilled Coloured workers. This transformation was also justified in economic terms to improve productivity. Employers in Paarl were not in favour of the policy of repatriation of the Africans, apart from being cheap; employers claimed that African labour was more productive and efficient than Coloured labour. While law no longer requires this practice, it still prevails and many people in Mbekweni have limited opportunities to secure employment in the Paarl District.

This pattern of job reservation confirms the findings of a study done by the International Food Policy Research Institute, University of Wisconsin and University of Natal which found that poor black South Africans are socially excluded from economic resources as it was found that they lack connections to people in better economic positions who could find them jobs. They lack access to loans and other support that could take them out of poverty.

The study concluded that the notion of social capital as a means to better people's lives is ineffective and inadequately constructed in a country where socio-economic inequalities exist even amongst the poor (<http://www.irinews.org/report>, 2007).

Several studies have critically examined the concept of 'social capital' for instance Andries Du Toit, Andrew Skuse and Thomas Cousins, (2005) conducted an ethnographic study of 'social capital' in the rural Eastern Cape. Though neither negating the existence of 'social capital' nor pushing it further to social exclusion, the authors suggest a critical analysis of the concept as a strategy for poverty alleviation. They propose the use of qualitative methodologies that would allow for an alternative understanding of experiencing poverty, as they found that social capital embeds a complex relation of exchange of goods and cash transfers, costs and benefits of creating and recreating relations, claims and counterclaims, social meanings, and unbalanced life decisions (Du Toit et al, 2005). Sandra Wallman (2005) supports the notion that social capital is only a model to think with and has limited capacity to explain diversified lived experiences in a given social context. She contends that social capital is not a network of contacts that are lifeless or people assume it is inevitable that people with some commonalities will unite. Wallman concludes that the definition of social capital lacks the meaning that brings people together, that is a sense of trust.

Mr Mgajo, the speaker for Drakenstein municipality said the level of poverty in Drakenstein region has increased to 35% between 2005 and 2006 (personal communication, 2006). The regional total average income was R5495 and for African families it was R1679. Twenty one percent of the 194, 419 families in the region who lived off under R800 a month were Africans. The report showed that Africans also constituted 60 % of unskilled workers, 14% of the unemployed and 25% of people with no income. Mbekweni is among the areas that recorded the bulk of people who lived on less than R800 a month (Integrated Development Program Report, 2005/2006). Elderly people complained that they carry the burden of supporting their unemployed children, despite having spent money on educating them.

A female participant commented that,

Many people had jobs but now our children are depending on us, on our old age grant, we just are paid for them to pay tuition fees, to buy food and buy uniforms. Siyalamba akukho nto intle- we are hungry there is nothing good.

I have noticed a strong presence of middle-aged men normally hanging around street corners or in the hostels who play the popular game of dominos. Many people depended on seasonal farm work, mostly available from September through to April. Nkeru, a female participant, considered seasonal farm work as a 'perverse opportunity' as she claims that it was responsible for lack of resilience and motivation for schooling among the youth because there is always a prospect of some cash, which is a short term solution. In other words, farm work has partly delayed personal and economic advancement. Berger (1990) has drawn the same conclusion about the predominance of women in union activism in the factories around Paarl, in the 1940s to 50s, that it was possibly as a result of their predominance in seasonal labour which gave them few options to improve their personal situation. As Mpondo, an elderly woman said about her situation and of others, who have had similar experiences, '*We have worked on farms even in cold weather but we are still poor even now*'. Mpondo is the product of those generations that experienced the deprivation of opportunities to accumulate wealth. She implied that her involvement in this process, because of historical structural control, was only to sell her labour for a meagre wage of between R200 and R240 a week, to those who control the products and profits (Khoza, 2007).

It is not surprising that the South African Institute for Race Relations found that there has been an increase in demand of welfare grants in the last ten years. The report states that poor socio-economic conditions and soaring food prices have pushed up poverty levels in South Africa (E-News Edition, 13.11.2007). As a woman from the sewing project said, *I do not know how people would survive if there was no social grant, ngesisifa – we would be dying of hunger.*

One of the present governments' strategies to curb hunger and malnutrition is the promotion of community based capacity building and food production projects (Khoza, 2007). However, food production was not a viable option for the majority of the community in an urban setting. For instance, there is one community garden at Phola Park, which the municipality supports. People who were interested in gardening received seed from the municipality. Nevertheless, they people were dissatisfied with the administration of the project, and accused the coordinators of corruption, as they sometimes did not receive their implements. Non-governmental organisations namely, CWD, the Dutch Reformed Church and Ikhwezi community centre run the other three community gardens. The failure of agricultural activities among Africans is a result of the effects of urban renewal and apartheid legislation on agrarian livelihoods that set guidelines to farm only in designated areas, and conferred land rights and agricultural production to White farmers (Khoza, 2007).

Some participants said the small space they had in their homes had been used for shack dwelling for family; or for rental as additional income, especially to foreign nationals. Nora, a woman from the sewing group said foreign national are charged more rental, *these are the cows we are milking because they are from outside*. This may not be a reflection of xenophobic attitudes but a perception that people from foreign countries have better access to economic resources than poor South Africans have. Other participants in the group discussion said they used old baths to grow some vegetables.

Only three of the families were involved in occasional gardening. For example, Fiyo grows potatoes, and Mambe sowed cabbage, spinach and pumpkins. She said she did not mind if there was not enough food to eat, she often cooks *imifino*, made from cabbage and spinach leaves. Beshela's father started to sow spinach and they bought some chicks to keep, on a piece of land at the back of the house.

4.5 Trust and cohesion threatened by witchcraft accusations

The changing socio-economic conditions such as poverty and struggle for food have changed perceptions of social relations. People viewed whatever resources they have as a source of envy and under threat. While some associated witchcraft with an evil eye for one's success or superior position in life, others linked generosity to witchcraft. Although food sharing with the less fortunate is an expected human value, because food has become a scarce resource for people to share with neighbours, participants said some people might be suspicious of food sharing as having ulterior motives. Some families were also concerned about observing certain rituals to ensure good living. Fiyo's partner, Nombongo thought he was poisoned or bewitched in a shebeen when he used to drink umqombothi. She also claimed that he gets sick when he works in his garden insinuating that there is something evil in the garden, because Fiyo gets a good harvest. She said they took him to a traditional healer in Kraaifontein and he excreted spiders. Mambe was also discouraged to work in her garden because the pumpkins that she had grown sprouted beautifully but allegedly damaged by a baboon from the neighbourhood, which she and the neighbour suspected it was looking for food. They could tell it was a baboon because they noticed its footprints in the garden, and the wounds that were borne by their dog the following morning, which meant that the dog was fighting the baboon (according to local beliefs, the evil spirit only visits at night in the form of a baboon).

Misiwe had a wound on her leg, which does not heal. She suspected witchcraft because she registers local people for seasonal work on farms. When she has met her quotas those who did not get in accused her of jealousy and in turn, she suspects them of jealousy because of her position. Moya said the pain in his leg keep coming back because he was bewitched when he was young. When Beshela's father had not cooked his own meal, he only eats from their mother's plate because he fears that his family could poison him because of his bad relationship with them. When a tenant at Nodumo's dwelling died in a shack fire while sleeping, neighbours suspected her of witchcraft because her son died a while ago under similar circumstances.

Some people in the community who knew that Nofirst was living with HIV and an active member of the Treatment Action Campaign approached her to offer their support to those sick and suspected of hiding their HIV status. Nofirst said a friend of theirs who was living with HIV died shortly after their visit. Nevertheless, she was warned by some people not to visit people who were nearly dead because they would be suspected of witchcraft. Xolelwa, a home based care worker said some people with TB whom they have visited believed that they were bewitched but some with HIV do know that HIV transmits through sexual contact. Hilda had undergone a ritual for coming of age and she wore a traditional necklace. She also mentioned going to the Eastern Cape for the reburial of her late father in the right place, at which point the family decided to perform all the rituals that was pending. Nobantu was considering rituals for the children who tend to soil themselves, perhaps because she has delayed the rituals. Hellman (2007) argues that sorcery and witchcraft beliefs such as the above-mentioned often happen amongst groups who live in poverty, experience insecurity, danger, apprehension and feeling inadequate and powerless.

Mulling (cited by Scheper-Hughes and Lock, 1987) agrees with Hellman and points out that witchcraft and sorcery accusations were used in West Africa as 'metaphors for social relation'. In Ghana such accusations suggested anxieties over competitive markets introduced by capitalism. The less fortunate accused the successful ones of greed and individualism. Mulling argues that these are not only the relations of envy by unsuccessful people, as suggested by Forster (1972), underlying these accusations is resistance to the deteriorating traditional ways of life based on reciprocity, sharing, and family and community loyalty. Scheper-Hughes and Lock conclude that Mulling suggests that witchcraft and sorcery accusations are not only influenced by capitalist socio-economic relations, but rather in the context of the wide commoditization of human life such accusations are likely to be shaped by social distortions and disease in the body politic produced by capitalism (Scheper-Hughes & Lock, 1987).

Participants in the group discussions about timelines of food economy mentioned that it was difficult nowadays to share food with neighbours or the needy. Cats, an elderly woman said,

In the old days, you were free to give other's children some food without being suspected of witchcraft. I used to collect left over food and warm it, then I used call some children from the street to come and eat

Another elderly woman who lives in a hostel says,

One thing I liked about life in the hostels is that the so called amagoduka- the migrants were generous, they welcomed everybody as a result many people from the township spent time in the hostels...the amagoduka cooked in big pots...women ate together unlike now, people eat separately...in those days people lived happily and trusted one another, people did not suspect that they could be poisoned through witchcraft.

People in the community may be reluctant to accept offers from others not only for the fear of witchcraft, but because of the prevailing social relations in the township of 'what goes around comes around. An elderly man explained this in the group discussions,

I have listened to a story on the radio about a person who was struggling to get food and did not receive any aid except from the neighbours. Eventually the neighbours got tired of feeding him and complained that he never returns their food. So we have a similar situation in this community, those are the things ezicinezela ubomi babantu- that tip people's lives especially the elderly - kuphele ntoni la nto kwakusithiwa bubuntu- what is lacking is what used to be called humanity.

In the context of poverty, giving is not always about not expecting something back from the recipient, even amongst close kin. Giving means bargaining whether for money, food or other. Therefore refusing offers may be a strategy to avoid tensions and conflict that might ensue when the giver claims back at a time the recipient is unable to give due to economic constraints. Then people will have their own cultural interpretations of those relations.

According to Mauss (1967) in all societies, those who give willingly ought to receive them back at some point. In essence, the giver and the receiver engage in a system of reciprocity. He observed gift giving and receiving in ancient societies of Polynesia, Melanesia and North West America, and found that gift exchanges may be a source of private and public conflict if they are not accepted or returned. Msomi an elderly man referred to above retorted that in contemporary society people demand their return gifts because they lack *ubuntu*- humanity. It may seem that the Xhosa tradition has shifted from moral values of giving willingly to economical obligations of paying back because reciprocal relations were never expressed in economic terms although they have always been hidden and covered under various types of symbolic interactions, for instance bride wealth, labour and gift giving during ceremonies or exchanging agricultural yields. People often expect to receive practical and emotional support that they offered others.

4.6 Violence and Crime

Families were experiencing illness in the context of other social problems. For instance on my last visit to Moya's family, I learned of the robbery and shooting that had taken place in their house the previous weekend. Since Vusa was selling alcohol from his shack, the assailants came after closing time and demanded Vusa to sell them beer. When Vusa told them there was no more beer they kicked the door open, searched the shack and started shooting in the air. Stanza stayed in police custody for stealing. He was often not willing to give details about his background and social networks. Madlamini's son was in prison for house breaking. She was also looking after a small boy whose mother was in prison at the time. After a while, I heard that the son of this woman died from stab wounds. When a new Shoprite grocery store was ready to open up at the end of 2006, the elders were happy that they would save on travelling expenses to Paarl city centre but were also anxious about robberies, as Makazi, an elderly woman, said, *we will be victims of our own children, they rob us of our money and groceries.*

The unrest in the community, following a murder of a high school girl who had been out drinking at night interrupted my field. I had to accompany my assistant to the police

station several times since the murdered girl was a friend of her daughter and they had been together earlier that day. We also attended a memorial service that the local churches organised in the area. Youth organisations also called a community meeting to discuss solutions to the growing criminal incidents in Mbekweni. The youth reported that they are bored because of a lack of adequate recreational facilities. In 2007 the team from South Africa Broadcasting Corporation Channel 2, breakfast show visited Mbekweni for a live broadcast to discuss issues like housing and the lack of recreational facilities for the young (Paarl Post, Thursday 15, 2007).

Alcohol abuse is a major problem in the community in both poor and wealthy families. Participants in the focus groups said alcohol was a reason for sliding from wealth to poverty and many poor who are struggling, often use alcohol to cope with difficult circumstances. In nine of the ten families that experienced TB and HIV, and in four of the ten families without TB, alcohol use was a problem. Zili, an elderly woman said, *life was better in Mbekweni when there were factories like Laangerberg (canning fruit factory) there were a few who were not working, so after many people were retrenched from Laangerberg we started having a problem of alcohol abuse in Mbekweni.* Participants said they noticed that the people who are struggling with their status tend to drink heavily. Nala, another elderly woman from Phola Park peace committee said, *someone living with this disease, HIV has weakened ability to think straight. People do not open up about this disease – that is why they resort to alcohol.*

Some people believe that the youth become more careless about their lives during Christmas holidays as the community experience increased alcohol consumption, unprotected sex and teenage pregnancy. Teenage girls from poor households are reputed to have sex with older men to get money for food or alcohol (known as *kura* – meaning sex for alcohol and money), or run away, as Madlamini was asked by a friend to accompany her to look for her teenage daughter who ran away with three others to Cradock in the Eastern Cape.

Fiyo claimed that Nombongo's daughters smoked dagga and were sex workers. An elderly man who is a member of the Phola Park peace committee said there was a link between TB, AIDS, and poverty because, *all those things are from that ukukura, that ukukura plays a big role; it is this mkuro that causes AIDS because a person does a quick fix carelessly while they are under the influence of liquor.* When I asked if the girls do get the money from these older men, Pam, a peace committee member said some of them do not; *they are not doing it even for that because they will wake up sober the next morning without a cent.*

4.7 Coping or Struggling?

When employing ethnographic methods to explore the trajectory of illness and social inequities in Mbekweni, it is possible to reflect on factors that may facilitate down or upward mobility of the poverty trap. TB and HIV illness experience exacerbated the already bleak situation of employment and food insecurity since none of the informants was in permanent employment. Therefore, informants had no benefits from their employment other than the Unemployment Insurance Fund, which by law they could not claim simultaneously with the disability grant. It is within the context of stark urban poverty and rural neglect that households have to deal with TB and with HIV/AIDS. As Wikan (2000: 212) stated in her illness narrative ... 'do not ask what disease a person has, ask what person does a disease have', in other words who is falling ill with TB and HIV?

People of Mbekweni live in an environment where TB and HIV illness are 'waiting to happen', as Moya's mother expresses her concern,

Even my daughters are not right, I told them to go for an HIV test and they refused and said they were not sick. It was the same case with Moya, he was always sick, had mouth sores and a persistent flu, I told him to go for a test and he was angry with me and said he does not have le nto that is common out there. When the papers came back from the clinic and showed that he was positive, I said to him, there you are, what do you say now, I suspected that you have le nto.

Rugalema (2000) questions the relevance of the coping strategies framework and argues that 'coping' needs critical analysis of the costs involved, to reveal the factors that enable families to manage well, return to 'normal' livelihood or fail to cope. An elderly woman lamented, *our children are consumed by TB, there is no money coming into the house while you are sitting with death*. Families were anxious about death and careful to pay towards a funeral plan. Monakali's sister constantly fretted about his lack of responsibility, including his failure to keep up funeral plan payments. She said, *what would I do if he died; my problem is I personally do not want anyone to suffer when I am dead. I saw the suffering when my mother passed away; burying a person is not an easy thing, the same happened with my late brother*. Moya's mother echoed the same about Moya's behaviour; *he thinks there is a chance to rise from his death! he is not even paying for his burial plan, I cannot afford to pay for him as I am already paying for Vusa, since he has had an operation and he now has asthma, he could die any time, he is not a healthy person that is why I took out a burial plan for him*. Clearly, should these families experience death, it would be hard to recover financially.

The literature on coping strategies reports that in poor resource settings, people cope with illness demands by borrowing, using savings, withdrawing children especially girls from school to escape school fees or care for the sick, and sell off their assets (De Vaal & Tumushabe, 2003, Naidu, 2003, Booysen et al, 2004, Rugalema, 2000, Goudge & Govender, 2000). As Corbett (cited by Goudge & Govender, 2000) questions the assumption often made in the literature about the vicious cycle of ill health and poverty that the poor simply sell off their assets to meet illness costs. In turn, I question the asset-holding assumption as a sign of coping in Mbekweni. The study found that borrowing was common in all ten families but the sale of assets and use of savings happened in one family, during Speech's death. Also for Sams's funeral, the family used his savings. Nofirst and Moya's family managed to renovate the house and buy the furniture with funds from the land restitution case, and they spent the disability grant to acquire some assets.

Therefore, it is not easy for the poor to sell off their assets as they could not afford to buy without this external support or if they sold their assets, it would be difficult to replace them without substantial and reliable sources of income (Adato et al, 2004).

On one hand, the sale or lack of assets among the poor in Mbekweni exposes their hardships and on the other hand retaining assets masks other layers of poverty such as unemployment and food insecurity. Participants in the wealth ranking discussion agreed with an elderly woman who said, *I want to correct the house thing, we were still working with my husband and we would fill the house with furniture, I'm just making an example, then the job come to an end, and everything ends, we are left staring at these woods and the beauty of the house then we don't have food we are the same as the poor.* Ngconde, a man from Phola Park peace committee said, *no, don't look at these things that are here, and these TV's they wouldn't be here if we didn't get that money for land; it will be difficult when it finishes.* As it was evident in Nobantu's case, her wardrobe was taken away by a furniture store due to non- payment, although she managed to replace it later on she was indebted. Two elderly people who took part in the timelines group discussion confirmed that there was a time they did not buy food and sold some of their clothing items. An elderly man said, *I sold my expensive suite for only R200 because kumnyama akukho ndawo ujonge kuyo- the situation is bleak they have no alternative, the children are not working and the grant money takes long to come. Therefore, you resort to selling your assets.*

Participants reported that both earnings and expenditure in the community are highest in December when informal saving clubs and bonuses are paid, and most spending is on visits and ceremonies in Eastern Cape. After this expenditure, payment of school fees in January is extremely difficult. During the winter months, expenditure rises due to the increased costs of heating, food and health care. Informant said that there are more illnesses in the cold, wet winter months. The winter season is also a difficult time for job opportunities, and those who lived in informal settlements are prone to floods and shack fires.

For families with TB and HIV, disability grants often came some months into treatment, and were used on food, drink, burial plans, personal goods, clothes, home maintenance, debts, remittances and savings. Families without TB had a similar pattern of expenditure.

Families bought foods in bulks but insisted that the food they bought was not of good quality. Families may be food secure but nutrition deficient. Several studies on food and nutrition security have found that poor households cope with poverty by consuming a monotonous diet, which consists mainly of staple foods such as maize meal, samp and beans, rice and cheap vegetable and animal fats (Rose & Charlton, 2001; de Swardt et al, 2005; Vorster et al, 1999; Bonti-Ankomah, 2001, Unterhalter, 1982). Bethina, an elderly woman from the Dutch Reformed Church said, *we buy these big packets that are not nutritious because they contain starch only for instance rice, maize meal are starchy foods there are no vegetables, fruits, milk or eggs. You only save for these big packets so that they last for a month but they do not have nutrients to feed the blood.* Fat intake poses a risk of non-communicable diseases. Research found that the emergence of non-communicable diseases among urban Blacks has been characterised by increased levels of obesity in women, hypertension in men and women, and stroke, but low levels of chronic heart disease and large bowel cancer (Vorster et al, 1999).

Given the socio- economic context described here, it is likely that many people in Mbekweni are vulnerable to food insecurity and ill health. A cycle of poverty exists when, as stated in Chapter 3, families spend less on food to cater for other households needs. Conversely, when food needs take up a large proportion of household's human, material and financial resources, with little or nothing left to cater for other basic needs, the household is highly vulnerable to food insecurity (Bonti-Ankomah, 2001). As Mambe said, obtaining food was a struggle but at *the same time, we cannot ignore other materials such as curtains* suggesting that you cannot spend all your money on food, *because we want our places to feel warm and homely.* The physical and psychological impact of food and nutrition insecurity may undermine people's ability to earn a living since many people in Mbekweni derive their income from seasonal labour (de Swardt et al, 2005).

I agree with Pronyk's (1999) point that technical solutions to the control of TB and HIV have limited success, as people do not experience disease as separate entities from other social problems. Structural factors, namely, poor housing and sanitation, land issues, lack of access to education, unequal gender relations, violence, food insecurity, scarce job opportunities, unemployment, and unequal access to adequate health potentially undermine TB and HIV/AIDS control efforts. Although this ethnographic material is specific to Mbekweni, the findings represent a wider social context of the poor and marginalised. Therefore when conceptualising the spread of TB and HIV/AIDS among the poor, we need to consider how much control individual households can exercise under conditions of 'high risk' as mentioned above (Marks, 2002). For example, the Western Cape Province has recently experienced rapid urbanization, which is characterized by informal shack settlements that increased from 28, 300 in 1993 to 11000 in 2004; the number of households living in poverty increased from 25% in 1996 to 32% in 2001, while unemployment in 2003 was at 23%. TB related deaths in this region increased from 13, 870 in 1997 to 24000 and 129 in 2004. In addition, a high incidence of HIV continues to rise in African communities. (Cape Town Project, 2006, Esau et al, 2004). To ignore these structural conditions in South Africa when discussing health-disease and well-being/illness is to disconnect the present from the past.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

This study used TB illness as a lens to explore how people cope with adversity. The findings provide evidence that people's agency for health care is constrained by their lack of material resources, and not their failure to present early at diagnostic centres or abandon bio-medical treatment due to cultural beliefs. All nine completed their treatment course, although a 61 year old man had relapse TB. They emphasised that TB and ARV medication is effective even for the few who tried other forms of healing. The emerging themes in the conversations of many people ('the food that nourishes the blood' and 'if there was no grant we would die of hunger') indicates that financial security and adequate nutrition are pivotally important for strengthening the immune response of people affected with TB and HIV illness. People reported increased hunger and linked that to TB and anti-retroviral medication. People with TB and HIV have additional needs for 'special' foods rich in protein and carbohydrates. Families largely dependent on social grants tried their best to provide for the needs of the sick.

Ill health resulted in interrupted livelihoods as people stopped working when ill. Families temporarily experienced economic hardships to pay for private doctors and special transport in order to seek diagnosis and cure; some paid for healing rituals; and others for 'special' foods. External welfare support, namely free medication, state social grants, emotional and material support from NGOs were critically important to enable families to cope with TB, HIV, other chronic diseases and food insecurity. However, in the long term, since the grant and NGO aid is not aimed at sustainable livelihoods, structural factors namely, unemployment, crime, violence, alcohol and drug abuse, poor living conditions, gender inequalities, stigmatisation and marginalisation, threaten these families and continue to make them vulnerable to TB and HIV.

The study recommends that the initiative by the Mbekweni clinic, during the study period, to forge strong links with local NGOs to provide food aid for clinic attendees needs to strengthen. The collaboration between the clinic and NGOs needs to consider special needs during TB and HIV illness, as not all people received food aid when they needed it. Food aid organisation need to extend this support to other vulnerable people, without TB and HIV, as they were often struggling to have enough or food at all. In addition, in the group discussion people voiced their unhappiness that NGOs only provide food aid for PLWH, while many people in the community experience hunger and food insecurity.

The integration of TB and HIV/AIDS treatment support, and empowerment on stigma related issues would help people to cope better with the psychosocial impact of TB and HIV, as some were struggling with their HIV status but reluctant to join a support group for fear of stigma. Clear channels of communication between diagnostic centres for prompt diagnosis and follow up of smear positives samples could ease the costs incurred by families in search of a cure before TB diagnosis, and further risk of transmission in endemic communities as it took patients between two weeks and 12 months to know their TB diagnosis. The integration of traditional healers in TB diagnosis would assist in quick referrals of people with TB symptoms to health care centres, as the HIV/AIDS programs have initiated that process. Intervention efforts at community level need to consider structural problems, namely crime, violence, gender inequality, alcohol and drug abuse, food security, job creation and housing, as these problems render people susceptible to ill health.

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